

Exploring Body-Related Experiences among Individuals with Spinal Cord Injury

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## **Abstract**

Using modified constructivist grounded theory, the purpose of the present study was to explore body-related experiences, specifically body image, in people with spinal cord injury. A total of nine participants (five women, four men) who had a broad range of body image experiences (from very negative to very positive) were interviewed. Most participants explained experiencing a fluctuating body image that varied from day-to-day. Negative body image experiences were represented by appearance, weight concerns, and function with all body image experiences encompassed by self-presentational concerns and tactics (an unanticipated finding). Positive body image was represented by acceptance, appreciation and gratitude of the body. Interestingly, negative body image experiences were not found to be represented by the opposite of positive body image experiences as they were each distinct. These findings have direct implications for medical professionals in hospital and rehabilitation settings to understand the importance of body image after spinal cord injury.

*Keywords:* psychological health, well-being, quality-of-life, physical disability, body image

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## Introduction

### Body Image

Body image is a term that has been consistently agreed among scholars to be a multidimensional phenomenon (Cash & Pruzinsky, 2002). This complex concept reflects how we see, think, feel and act toward our bodies and these perceptions, thoughts, feelings, and behaviours can be positive and/or negative in nature (Cash & Pruzinsky, 2002; Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). Body image is also heavily affected by social factors (e.g., interpersonal relationships, society, the media, and cultural socialization), and therefore can be understood as a subjective experience which is open to change from social interactions (Grogan, 2007).

**Westernized ideal body type.** Many negative body image behaviours and experiences (e.g., extreme dieting or use of performance enhancing drugs) stem from the internalization of socialized ideals of appearance, particularly the westernized ideal body type. In Western culture, the ideal body figure for a woman can be described as White, thin, tall, young, and full breasted. Since the 21<sup>st</sup> century, the ideal for women has also changed to include visible lean muscle tone, still with the emphasis on thinness. Slimness is seen as desirable for women because it is associated with self-control, elegance, physical attractiveness and youth. For men, the ideal is characterized by visible muscularity and large muscle mass, specifically in the arms, chest, and back. For both genders, being overweight is seen as unattractive and is associated with negative characteristics such as laziness, lack of self-control and being less happy (Grogan, 2007). In addition, embedded in both these definitions of the ideal is the assumption of having an able-body, implying anyone who has a physical disability can never attain the ideal.

Very few people naturally have the ideal body type and therefore have to strive for and/or maintain the ideal figure through rigorous exercise and diet regimes. Those men and women who do not fit the narrow range of acceptable body appearances (including those who are not able-bodied) may face prejudice, discrimination, and other forms of social rejection. Overall, the westernized unrealistic ideals have been over-represented in the media, which has been linked to internalization of these ideals among many men and women, leading to negative body image experiences such as increased body dissatisfaction (Bordo, 2003).

**Drive for thinness.** One of the consequences of internalizing the Western culture ideal for women is the drive for thinness, a desire to be thinner (Fernandez & Pritchard, 2012). The media constantly reinforces messages to women to be thin by means of dieting and exercising. This is because much of a woman's worth is determined by her appearance, which since the 20<sup>th</sup> century has been focused around being thin. Along with the thin ideal came the push for women to purchase diet pills and spend an enormous amount of time and energy on making their bodies more slim (Hesse-Biber, 2007). Internalization of the thin ideal leads to the development of a cognitive schema that associates thinness with positive attributes such as happiness, social desirability and social status (Stice, 1997). Rewards, such as social desirability, are what push women to want to be thin. Research has shown an association between media, high drive for thinness and serious body-related eating disorders such as anorexia nervosa (Levine & Murnen, 2009). Overall, powerful media expectations of women to be thin have created a phenomenon, known as the drive for thinness, which contributes to women's obsession with changing their body to the ideal, which has been linked to body image disturbances.



**Drive for muscularity.** The body image literature has expanded over the last two decades to also include male body image concerns, such as the drive for muscularity. Early research suggested an overall positive body image among men as they traditionally accounted for a small portion of those with eating disorders and body dissatisfaction with regards to body fat and the drive for thinness. However, researchers began to realize this approach was problematic; it was not appropriate to assess men's body satisfaction with regards to wanting to be thinner because of gender differences in body type ideologies (McCreary, 2011). The standard for women is based on the thin ideal, whereas the standard for men is actually based on a muscular ideal where the focus is on the size and distribution of muscle mass. Therefore, male body image concerns have actually been underestimated.

The internalization of the muscular male body ideal produces a cognitive schema which associates this ideal with socially desirable characteristics (e.g., power, status, and masculinity) which can lead to extreme methods (e.g., use of performance enhancing drugs) of attaining the ideal. Researchers termed this desire to be bigger and more muscular as 'the drive for muscularity' (McCreary, 2011). McCreary and Sasse (2000) found higher levels of the drive for muscularity to be correlated with lower self-esteem and higher depression scores. In addition, they found wanting to be more muscular to be associated with increased use of anabolic steroids and other performance enhancing drugs. Overall, although adolescent boys and men do not show increased body dissatisfaction with regards to body fat, they do show lower self-esteem and higher depression rates when their drive for muscularity is high.

**Outcomes of negative body image.** The discrepancy between Western society's obsession with body shape and thinness ideals and the reality of actually being able to achieve these ideals has been linked to negative body image experiences such as body dissatisfaction (Levine & Murnen, 2009). These negative body image concerns have been linked to numerous negative health-related outcomes. For instance, behaviours such as eating disorders, excessive physical activity as well as inactivity, smoking, dietary restraint, steroid use, and unnecessary cosmetic surgery (e.g., Grogan, 2007; Grogan, 2006; Hesse-Biber, 2007; McCreary & Sasse, 2000) are associated with negative body image. Negative body image has also been linked to negative psychological outcomes such as depression, anxiety, and low self-esteem (e.g., Olivardia, Pope, Borowiecki III, & Cohane, 2004; Sides-Moore & Tochkov, 2011).

**Individual differences in body image.** Research on body image has started to broaden to examine racial differences, life course changes, and differences according to sexual orientation. For example, it has been shown that Black women tend to have larger bodies and more positive body image than White women. Many Black women actually report a larger body ideal and often have higher body weight relative to White women. Research has consistently found that Black girls, relative to other ethnic groups, have higher body satisfaction and do not strive for the thin westernized ideal (Franko & Roehrig, 2011). In addition, evidence suggests that Black males also have a greater preference for women with a larger body size and have a more positive body image than White males (Ricciardelli, McCabe, Williams, & Thompson, 2007). However, research has also begun to show ideals are starting to become more culturally homogenous in the

last decade (Grogan, 2007). In other words, body image differences based on ethnicity are declining.

Research in body image has also begun to investigate middle-aged and older adults. Although physical development is complete by the end of the teenage years, the body continually changes until death. Research has shown that older adult men and women may display low negative body image despite the fact their body appearance is moving away from the ideal (Whitbourne & Skultety, 2002). This may be explained by a change in ideal to more realistic standards as adults' age, moving away from unrealistic body ideals, as they are less relevant. Decreasing ideal standards may also decrease the discrepancy between ideal appearance and actual appearance. Older adults may also place higher value on other aspects of the body, such as functionality, and may deviate away from focusing solely on appearance (Grogan, 2007).

Even with the expansion of research including other ethnicities and age groups, body image research is still based predominately upon White healthy able-bodied college and adolescent students (Cash & Smolak, 2011), which is a key limitation in the field. There is a large demand for research that investigates other samples, such as individuals who have a physical disability. This area is important not only because little is known about their body image experiences, but because they do not fit the standards of the westernized ideal body type due to their disability. Therefore, research concerning individuals who have a physical disability is imperative.

**Positive body image.** Much of the theory, research, and practice in body image has focused largely on the improvement, prevention and treatment of negative body image outcomes. Examples of this focus on body image as a negative construct include

body image disturbances contributing to disordered eating behaviours, negative influences from the media, drive for thinness, drive for muscularity and overall body dissatisfaction (e.g., Stewart & Williamson, 2004). Researchers have argued that by only deconstructing negative body image we still do not have a full understanding of body image and psychological health. As stated by Keyes and Lopez (2002) “mental health is not merely the absence of mental illness” (p. 48). Much to the same respect, the absence of negative body image does not necessarily mean positive body image exists. Positive body image is distinct from negative body image. Positive body image does not mean someone thinks his or her body is perfect and physically attractive in line with the cultural ideal. Rather, anyone can have positive experiences of the body, including for example, those who are overweight, from minority ethnic groups, or who have a disability (Tylka, 2011).

In an attempt to describe characteristics of positive body image, Frisen and Holmqvist (2010) analyzed interviews from adolescent girls and boys using a thematic approach. The participants were selected from an ongoing longitudinal Swedish body image study and were chosen based on self-reported high levels of body-esteem as measured by the Body Esteem Scale for Adolescents and Adults (BESAA; Mendelson, Mendelson, & White, 2001). There were 30 participants, with an equal number of boys and girls, who were in the 97<sup>th</sup> percentile or above in the BESAA scores. All participants showed similar characteristics for positive body image such as satisfaction with their own appearance, a functional view of the body, the assumption of others liking one's appearance, not giving importance to negative comments, and positive influences from family and friends. However, there was one main gender difference in regards to

appearance. The girls mentioned a greater number of body parts they were either satisfied or dissatisfied with in comparison to boys who talked about their body as a whole. Past research has supported this gender difference, as women tend to view their body in distinct parts, whereas men tend to view their body as a singular and complete entity (Halliwell & Dittmar, 2003).

In a separate study examining positive body image, Wood-Barcalow, Tylka, and Augustus-Horvath (2010) interviewed 15 female college students who were classified as having a positive body image (determined using the 7-item Appearance Evaluation subscale and 4-item Overweight Preoccupation subscale of the Multidimensional Body-Self Relations Questionnaire) and 5 female experts in the field of body image. Experts were faculty and clinicians with an average of 25 years of experience studying body image. They used a grounded theory approach to generate themes from the data and found several positive characteristics to emerge, including: appreciation of the body, unconditional acceptance from others, body acceptance and love, spirituality/religion, and taking care of the body.

In addition, quantitative work by Avalos, Tylka, and Wood-Barcalow (2005), which sampled American college women, has also investigated positive body image and found that having favourable opinions of the body, body acceptance, respect for the body by listening to its needs, and protecting the body by rejecting unrealistic ideal body images were associated with psychological well-being. These qualities were used by the authors to develop the Body Appreciation Scale (BAS) and are consistent with earlier research by Williams, Cash, and Santos (2004). This research also showed that women with positive body image reported several aspects of well-being such as self-esteem,

optimism, weight stability and active coping. These aspects of well-being that have been found have reinforced the importance of characteristics such as spirituality and religion, inner positivity, and broadly conceptualizing beauty (e.g., Homan & Boyatzis, 2010; Wood-Barcalow et al., 2010).

Tylka (2011) synthesized findings from studies of positive body image (e.g., Avalos et al., 2005; Frisen & Holmqvist, 2010; Wood-Barcalow et al., 2010) and found that similar characteristics emerged across the different samples. Nine characteristics were identified. Body appreciation refers to appreciating all aspects of your body including functionality and health and not just appearance. Body acceptance and love is accepting the body regardless of the fact you may not be completely satisfied with all aspects. In addition to these core characteristics, Tylka (2011) identified characteristics that help promote and maintain positive body image. Broadly conceptualizing beauty is characterized by believing a variety of body shapes and sizes are beautiful. Media literacy involves having an understanding of the fabricated nature of the media. Perceiving unconditional acceptance from others (such as family and friends) involves feeling loved for qualities other than appearance. Finding others with a positive body image and being spiritual or religious (i.e., perceiving a higher being has designed everyone to be unique and different) also contribute to positive body image. The last characteristics are thought to emerge from positive body image and includes inner positivity influencing outer demeanour (refers to believing inner qualities such as optimism and happiness are reflected in one's outer appearance) and listening to and taking care of the body. For instance, those with positive body image engage in positive behaviours and activities for intrinsic rewards and health benefits (e.g., exercise for stress relief).

To conclude, positive body image can be understood as overall love and respect for the body. It provides a positive schema in which incoming positive information is internalized and incoming negative information is quickly rejected or reframed. This includes acceptance of the body and not internalizing socialized ideals. Overall, individuals who have a positive body image display confidence and happiness with their bodies (Tylka, 2011).

### **Self-Presentation**

Self-presentation (also known as impression management) refers to the process by which individuals engage in behaviours to control and monitor the impressions others form of them (Leary, 1995). Impressions people form of others can have direct implications on how others are perceived, treated, and evaluated. Therefore, individuals sometimes behave in order to be perceived in a certain way in other's eyes, often for social rewards or desirability (Leary & Kowalski, 1990). For example, there are many social rewards that accompany being viewed as physically attractive such as being perceived as more sociable, dominant, and intelligent (Leary, 1995). People generally want others to view them in a desirable way, thus, they attempt to control the inferences made by others by presenting only information about themselves that will bring about the desired impression while also hiding information that is inconsistent with the desired social image.

Physical appearance can be understood as the most apparent nonverbal exchange of self-expression and therefore others quickly form impressions based on appearance. Efforts made to improve physical appearance may be understood as conscious or less conscious. Conscious efforts are referred to as self-presentational tactics and may include

decisions about hairstyle or clothing. These decisions are made not only from personal preference, but also on how these decisions will be regarded by others. Clothing in particular conveys a clear impression on others and therefore clothing choices are often heavily influenced by these impressions. Less conscious efforts to improve appearance may be combing hair, putting on make-up, or ironing clothes. Although there is less of a conscious decision to make an impression on others, if the motivation to make a favourable impression was absent, then it is less likely these tasks would be completed (Leary, 1995).

Impression management may be used to increase subjective well-being. First, self-presentation allows people to maximize their reward-cost ratio in social relations. Conveying the right impression may increase the likelihood of obtaining desired outcomes such as approval, friendship, or power. Self-presentation helps to enhance one's self-esteem through regulation such as receiving compliments or praise for a certain impression. Lastly, self-presentation may facilitate the development of desired identities. People engage in impression management as a means to creating identities or ideal selves. People are more likely to impression-manage when the impressions they make are relevant to one of the goals discussed above (social and material outcomes, self-esteem maintenance, identity development; Leary & Kowalski, 1990).

Self-presentation conceptually overlaps with body image; however, it is also a distinctly separate concept. Someone's body image may influence their self-presentation and vice versa. For example, if someone has a positive body image and feels confident then it may be important for them to present themselves in a confident manner and to be perceived by others as confident. Furthermore, by presenting oneself to others as



confident this may have a positive influence on body image. The distinguishing factor between body image and self-presentation is that body image encompasses thoughts, feelings and perceptions about one's own body whereas self-presentation involves the beliefs about the perceptions of another person (i.e., the image you are conveying to someone else). Therefore, although these two concepts influence each other, they are also distinct.

### **Spinal Cord Injury**

As noted earlier, body image research for those with a physical disability is an important area of investigation and is limited in the current literature. This is especially true for individuals with a spinal cord injury (SCI). A SCI results in immediate physical impairments consequently resulting in a changed body. Such changes include changes to appearance (e.g., loss of abdominal muscle tone referred to as 'quad belly'; Chau et al., 2008), functionality (e.g., changes in bladder/bowel function; Benevento & Sipski, 2002), and independence (e.g., the dependence of others or adaptive devices for transferring; Galvin, 2005). These changes that occur to the body likely move it away from the Western culture ideal body type which then may lead to more negative body image (e.g., increase body dissatisfaction or decrease body esteem). A discrepancy between actual body type and the ideal has been found to increase body dissatisfaction in adolescents (Furnham, Badmin, & Sneade, 2002). Similar disturbances may occur in people with SCI because of the marked changes that occur to the body following injury. Therefore, research in the area of body image and SCI is important.

Spinal cord injuries result from traumatic (e.g., motor vehicle accident) or non-traumatic (e.g., virus) injuries. Individuals who have a SCI will experience impairment of

the communication between their brain and the rest of their body. This impairment affects several body functions including, for example, mobility, sensation, regulation of body temperature, and bladder and bowel function. Damage to the vertebra or spinal cord can cause a partial or full lesion in the spinal cord. A total loss of sensation and movement at and below the injury is due to a complete lesion. Paraplegia is the result of a lesion located at the level of the thoracic vertebra or lower in the lumbar and/or sacro-coccygeal regions and results in impairment of sensation and movement of the lower trunk and limbs. Tetraplegia (otherwise known as quadriplegia) is the result of a lesion in the cervical vertebra. This results in impairment of motor and/or sensory function in the upper and lower extremities, trunk and pelvic region (Somers, 2010). Impairment to body sensations and functions may in turn influence experiences of embodiment (since embodiment is the awareness and responsiveness of the body; Arzy, Overney, Landis, & Blanke, 2006). Therefore, body image can be understood as particularly important for those who have a SCI as it may be related to overall well-being (e.g., Chau et al., 2008; see also Taleporos & McCabe, 2002).

Much of the work on SCI and body image has investigated the negative implications, such as struggles with conformity to masculine gender roles, changes to sexual self-esteem and negative changes to overall functionality (e.g., Burns, Hough, Boyd, & Hill, 2010; Potgieter & Khan, 2005). However, some research has investigated satisfaction with appearance and functionality among individuals who have a SCI. For example, a study by Bassett and Martin Ginis (2009) looked at body image (satisfaction with appearance and satisfaction with functionality) among men who have a SCI. They predicted that those who perceived their body image to have a negative impact on their

quality-of-life would be more likely to engage in leisure time physical activity to improve their body image. Results indicated that men were generally satisfied with their appearance (levels similar to the general population) and that body image did not motivate physical activity. These researchers suggested this could be due to those with SCI placing relatively little importance on appearance compared to factors such as functionality. However, considering the functional limitations that follow a SCI it is surprising men were also generally satisfied with their functionality. This may be due to the fact that men lower their functional standards after a SCI leading to lower dissatisfaction, although this was not directly investigated. These results suggest that people with a disability do not necessarily have increased body dissatisfaction.

Another study by Bassett, Martin Ginis, and Buchholz (2009) investigated women with SCI and their body image. This pilot study demonstrated that women in their study were slightly dissatisfied with their appearance and slightly satisfied with their function. Appearance satisfaction was found among the women with a smaller waist circumference, a lower percent body fat, and greater years post-injury. Interestingly, appearance was not related to any of the leisure time physical activity variables. Lastly, functional satisfaction was highest among the women with greater years post-injury. This study suggests that body image may improve among individuals with a SCI as they become more adjusted with their injury and are further post-injury.

A study by Chau and colleagues (2008) investigated women's perceptions of their changed bodies after a SCI. They found a fluid three-phase process about living with their changed bodies during the span of early rehabilitation to community reintegration: the first stage was discomfort, the second was moving towards comfort and the last stage

was comfort. Discomfort was related to the changed physical body, loss of control and altered social reactions with loss of control being the primary factor that negatively influences self-concept. The researchers found that during the early phases of rehabilitation, emotions with regards to the self are generally negative. A new physical appearance and new lifestyle adjustments were found to present a great challenge during recovery. Comfort was achieved by participants who openly discussed their issues related to living with a SCI. Participants comfortable with their changed bodies described a sense of responsibility to educate others around them to make the public more accepting of their appearance. Overall, participants needed time to rediscover their abilities and find methods to lead fulfilling lives. Adjustments to a new self and body are facilitated through higher social support and positive social interactions.

Research on SCI and self-concept (of which body image may be considered one aspect), also supports the possibility that positive psychological changes may occur following SCI. Sheldon, Renwich, and Yoshida (2011) found three main themes for self-concept among men with a SCI: (1) changes in the self and the body, which reflected the men not feeling whole, along with engaging in an ongoing negative self-talk; (2) interactions with the public and the impact on the self, which comprised of feeling judgement toward the self through the public lens; (3) decisions and actions people take, which comprised more positive outcomes such as feeling lucky and seeing positive change to their life since their injury by having more opportunities than limitations. Of these three themes, more negative outcomes of SCI were discussed than positive. However there was important evidence for positive adjustment after a SCI. Together these studies provide evidence that suggests positive outcomes to self-concept can

emerge after adjustment to a SCI (e.g., Sheldon et al., 2011; Potgieter & Khan, 2005).

Furthermore, these studies (Bassett & Martin Ginis, 2009; Bassett, Martin Ginis, & Buchholz, 2009; Chau et al., 2008; Sheldon et al., 2011) suggest then, that negative body image is not necessarily experienced by all individuals with SCI, and that body image may become less negative as these individuals move further post-injury.

Given this very limited research, there is a need for further exploration of what defines, builds, promotes, and maintains a positive body image among those who have a SCI. There is lack of research that focuses on positive body image for individuals with disabilities as most research on positive body image has focused predominately on able-bodied, White individuals (Tylka, 2011). Many of the same characteristics that promote positive body image found in previous research (e.g., Frisen & Holmqvist, 2010; Wood-Barcalow et al., 2010) synthesized by Tylka (2011) may apply to those with a disability such as a SCI. Examples of characteristics that may apply to both able-bodied individuals and those who have a SCI might be: unconditional acceptance from others, being spiritual or religious, and finding others with positive body image. After acquiring a SCI, having unconditional support from people who love you may be imperative especially during the adjustment period. Having people accept your body, regardless of your appearance and functionality, is likely to be a key aspect to positive body image for people with a SCI. Some may turn to religion for faith to feel they are just as important of a human being as the rest of the population and that if anything their disability makes them unique. Lastly, it may be important for people with a SCI to surround themselves with others who have a positive body image to remind them of the ways in which they can feel positive about their body.

## **Critical Disability Theory**

The conceptual lens for the current study was underpinned by Critical Disability Theory (Pothier & Devlin, 2006). Critical Disability Theory was developed for the study and analysis of disability issues and describes the complex social systems which oppress those with a disability. This theory outlines disability as a social construct and not a consequence of impairment. It was designed to deconstruct the ingrained privileges of having an able-body since societal structures and assumptions are based on able-bodied norms. The goal of Critical Disability Theory is to challenge these assumptions and presumptions so individuals with disabilities can more fully participate in society (Pothier & Devlin, 2006). The dominant paradigm for understanding disability has been through the medical model which identifies the disadvantages experienced by individuals with a disability as defined by their medical condition. This attitude is particularly displayed among clinicians who often refer to their patients by the disability they have rather than the person they are (e.g., osteoporotics, rather than people with osteoporosis; Hosking, 2008). Understanding the social construction of disability was imperative when interviewing people with SCI, especially when dealing with a sensitive topic such as body image. Social construction of the meanings behind disability is crucial in the understanding of the intersectionality experienced by those who have a SCI. It was important to have a conceptual lens to unravel the inherent complexities associated with disablement and the inequalities with which were associated (Pothier & Devlin, 2006).

Experiences of embodiment for someone with a SCI were, in part, influenced by their experiences of marginalization. Since disability can be understood as a social construct in which inequality is purposefully designed and maintained by the status quo,

the experience of a disability is therefore heavily influenced by political norms already in place. When disability is interpreted as a social construct, it is examined under the socio-economic, cultural, and political disadvantages resulting from social exclusion (Baffoe, 2013). How someone with a disability experiences his/her body, whether it is positive or negative, was partly determined, by the experience of disablement. In addition, body image is also socially constructed and was therefore understood under the same theoretical lens (Grogan, 1999). To have a true subjective understanding of someone's experience with the body, particularly for those with a SCI, the perspective of Critical Disability Theory was appropriate.

### **Purpose**

The purpose of this modified constructivist grounded theory study was to broadly explore body image experiences among individuals who have a SCI. The following overarching theoretical question was investigated: How are body image experiences represented for someone with a SCI?

### **Thesis Format**

For organizational purposes, the studies presented in this thesis were written as independent journal articles. Since negative and positive body image questions were organized separately in the interview guide and these experiences were described as distinct by participants, two independent journal articles were deemed appropriate. Each article includes a brief literature review, purpose, theoretical questions, methods, results, conclusion and implications, and limitations and future directions. Therefore, there is overlap of sections within the entire document. However, a final discussion provides an

overall perspective on the two articles and the empirical contribution each have in the existing body image and SCI literature.



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## **Article 1: Managing the Stigma: A Pilot Study Exploring Body Image Experiences and Self-Presentation among People with Spinal Cord Injury**

Body image has been conceptualized as a multidimensional concept reflecting perceptual, cognitive, affective, and behavioural aspects (Cash & Pruzinsky, 2002; Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). Body image can be experienced positively or negatively and affects many aspects of psychosocial well-being and quality-of-life (Cash & Smolak, 2011). Many negative body image experiences (e.g., dissatisfaction) stem from the internalization of cultural ideals of appearance, particularly the westernized ideal body type. In Western culture, the ideal body figure for a woman is White, thin, tall, young, and full-breasted, with some visible muscle tone (Grogan, 2007). For men, the ideal is characterized by visible muscularity and large muscle mass, specifically in the arms, chest, and back (McCreary, 2011). Internalization of the ideal leads to the development of a cognitive schema that associates attaining the ideal with positive attributes such as happiness, social desirability and social status (Stice, 1997). Embedded in the ideal for both men and women is the assumption of having an able-body, implying anyone who has a physical disability can never attain the ideal. Regrettably, most of the body image research has focused primarily on able-bodied female college and adolescent students' experiences, overlooking body image experiences in other samples (e.g., people with physical disabilities) which has been recognized as a major limitation by experts in the field (e.g., Cash & Smolak, 2011).

One example of a physical disability that results in many physical changes to the body is a spinal cord injury (SCI). Many SCIs occur as a result of trauma to the vertebral column and/or spinal cord, resulting in impairment of motor and/or sensory function in

the upper and lower extremities, trunk and pelvic regions, as well as autonomic impairments such as bladder or bowel function (Somers, 2010). These changes can in turn affect appearance, functionality and independence (e.g., Galvin, 2005) which can all influence body image. These changes to the body take those who have a SCI away from the ideal which may then lead to more negative body image. Research found that those who have a SCI experience struggles with conformity to masculine gender roles, changes to sexual self-esteem and negative changes to overall functionality (e.g., Burns, Hough, Boyd, & Hill, 2010; Potgieter & Khan, 2005).

Few studies have investigated body image specifically in people with SCI. Bassett, Martin Ginis, and Buchholz (2009) investigated women with SCI and their body image (appearance and functional satisfaction). Women in their study were slightly dissatisfied with their appearance and slightly satisfied with their function. Appearance satisfaction was found among the women with a smaller waist circumference, a lower percent body fat, and greater years post-injury. Lastly, functional satisfaction was highest among the women with greater years post-injury. Another study by Bassett and Martin Ginis (2009) looked at body image (appearance and functional satisfaction) among men with SCI. Results indicated the men were generally satisfied with their appearance and function. The authors proposed this may have been due to the men lowering their appearance and functional standards following their injury by shifting value away from physical qualities or changing the reference group (to other men with SCI). However, no research has used an in-depth method to further explore these suggestions.

One concept closely related to body image is self-presentation (also known as impression management). Self-presentation refers to the process by which individuals



engage in behaviours to control and monitor the impressions others form of them. These impressions are important because they can impact how people are perceived, treated, and evaluated by others. For example, there are many social rewards that accompany being viewed as physically attractive (i.e., meeting the cultural ideal) such as being perceived as more sociable, dominant, and intelligent (Leary, 1995).

Since physical disability has been found to negatively impact body image (e.g., body esteem) in people with acquired disabilities (e.g., SCI and multiple sclerosis; Taleporos & McCabe, 2001), it may also impact self-presentation. For instance, according to the North American ideal, people who have a SCI can never attain the ideal due to discernible aspects of their disability (e.g., use of a wheelchair). Therefore, despite their best efforts, their social image may be threatened by their physical disability. For instance, others may not perceive them as physically attractive. Consequently, individuals with a SCI may experience stigma. Particularly when a physical disability is visible to the public-eye others may regard them as deviant, flawed, or undesirable. People often react negatively to others' flaws which can lead to negative inferences made about that person which then form into a stigma (Goffman, 1963). People not only evaluate stigmatized people unfavourably (e.g., unattractive, impotent, asexual), but also behave differently toward them. Therefore, individuals who experience stigma (e.g., people with SCI) may engage in a number of self-presentational tactics to minimize the impact of stigma. Although body image and self-presentation are two distinct constructs (body image being one's own perception of the self and self-presentation being how people believe others may view the self), these constructs also overlap. For example, self-presentational concerns about appearance, perhaps induced by experiences of stigma, may create poorer

body image. Furthermore, a negative body image may produce greater self-presentational concerns. Currently, there is no in-depth exploration of body image and self-presentation in people with SCI in the literature. It is likely that in those with SCI, the impressions others hold of them may have an impact on their body image.

In able-bodied samples, body image experiences have been shown to influence health behaviour by either encouraging or discouraging certain activities (e.g., engaging in physical activity or healthy eating habits; Furnham, Badmin, & Sneade, 2002).

Therefore, it would be useful to have an in-depth understanding of body image in people with SCI as there may be direct implications in hospital, rehabilitation, and exercise settings to improve the well-being and quality-of-life of those living with a SCI. This leads into the purpose of this study which was to broadly explore body image experiences among people with SCI. The following theoretical question was explored: How is body image represented for someone with a SCI?

## **Method**

### **Participants**

Nine participants from southern Ontario who had a SCI were recruited for this study (five women and four men). To the researchers' knowledge this is one of the first studies in the body image and SCI area, therefore flexible inclusion criteria was implemented. Participants were included if they met the following criteria: 18 years or older, at least 12 months post-injury, and no history of a clinical eating disorder. Those who had a history of an eating disorder were not included due to the fact they may have a much more extreme body image (e.g., severe disturbances). Participant characteristics can be found in Table 1-1. All names are presented as pseudonyms to protect the

confidentiality of participants. Although geographically and culturally this sample was homogenous (predominately Caucasian residing in the Niagara Region), there was much variability in participant characteristics (e.g., age, gender, level of injury, completeness of injury, physical activity level) demonstrating a diverse sample.

### **Research Team**

The research team comprised four individuals (all Caucasian), who had varying levels of education and research experience. All members of the research team were part of the development of the interview guide and over-arching concepts of the data. The primary researcher, researcher A (first author), was a 25-year old female Master's student. She was 162 cm tall, weighed 123 lbs (body mass index = 21.30), and had a petite build. She was a novice researcher in the area of body image and SCI. She developed the research idea, conducted the project, and transcribed and analyzed 100% of the data. At the time of the study, researcher B (42 years of age) had extensive research experience in the area of body image and self-presentational concerns across the lifespan. Her experience includes investigating the impact of body image and self-presentation on psychological states and health behaviours, using both quantitative and qualitative approaches. She coded and analyzed 30% of the data and played a major role in the refinement of concepts, categories and subcategories that emerged from the data. Researcher C (43 years of age) had extensive experience in qualitative methodologies and played a major role in guiding the rigour of the research design. Lastly, researcher D (42 years of age), had extensive expertise in the area of SCI. He was the director of the Neuromuscular Rehabilitation Lab at the university and was involved in recruitment of participants.

## **Study Design**

A modified constructivist grounded theory (GT) was employed for the current project. Constructivist GT is a much newer approach to GT than the more traditional ones designed by Glaser and Strauss. Constructivist grounded theorists take on a reflexive stance toward their research process and explicitly assume an interpretative view (i.e., multiple realities exist) and that any analysis is contextually situated in time, place, culture, and situation (Charmaz, 2006). When grappling with the social construction of body image and disability, it is informative to have an interpretive view to truly understand the meaning behind the subjective experiences of embodiment. The reality and experiences of the body for someone with a SCI may be much different than for a researcher who does not have a SCI. This GT study is modified by having fewer interviews compared to traditional GT studies which comprise up to 30 to 40 interviews. Since this was a pilot study and was one of the first to explore in-depth body image experiences in people with SCI, a modified GT was implemented for exploratory purposes. Modified GT has been successfully conducted and suggested by past researchers (e.g., Cutcliffe, 2005; Kearney, Murphy, & Rosenbaum, 1994). This approach remains rigorous with the ultimate goal to develop a preliminary model. Our preliminary model (Figure 1-1) was generated inductively through an iterative process through which new data was constantly compared to emerging codes, categories, and concepts (Charmaz, 2006).

## **Procedure**

Data was collected as part of a larger study investigating overall body image experiences (e.g., positive body image) and physical activity in people with SCI. Upon

university research ethics clearance (see Appendix A), participants were recruited using purposive sampling procedures known as snowballing (Patton, 2002). The first participants were recruited by Researcher D (through the exercise facility associated with the university) and then interested participants were asked if they knew others who may be interested in participating who fit the inclusion criteria. Once participants displayed interest in the study, they were emailed a letter of invitation (see Appendix B) outlining details of the project, the Leisure Time Physical Activity Questionnaire for People with SCI (LTPAQ-SCI; see Appendix C), and the one-on-one interview guide (see Table 1-2 and also Appendix D). Then, participants were scheduled for a telephone and an in-person interview. Telephone interviews were completed first where participants provided verbal informed consent and the interviews were about 15 minutes in length.

A common method used in GT research is in-depth interviews. In cases of sensitive subject matter, individual in-depth interviews provide an effective tool to create an environment where participants would be likely to speak more openly (Liamputtong, 2009). For the purpose of this project, interviews were semi-structured allowing the flow to be determined by the respondent and the researcher to explore unexpected material as it arose (Patton, 2002). The main questions were developed using the definition of body image, whereby the four components were broken down into questions (e.g., how do you see your body?). In addition, questions were designed to probe about before, acutely after injury and currently to explore changes in body image overtime. Interviews took place on the university campus in a private office or at the participant's own home. Upon arrival to the in-person interview, participants provided written informed consent (see Appendix E) and completed general demographic information (see Appendix F). The one-on-one

interviews ranged from 60 minutes to 2 hours in length and participants were offered a break midway through the interview. Then, a few weeks later two participants (Caroline and Danny) were recruited to do a follow-up interview to elaborate on specific concepts. Follow-up interviews lasted about 60 minutes. All interviews were audio recorded for transcription purposes and participants were compensated \$20 for their time.

To ensure authenticity, credibility, and trustworthiness of the data, we followed Lincoln and Guba's (1986) recommendations. Member checking was used to ensure proper terminology, sensitivity and definitions of concepts were interpreted properly. Within one week of each interview, participants were provided by email a summary of their interview to review for misinterpretations. To maintain authenticity, participants' own words are displayed as quotations in the results. Two independent coders were used to ensure trustworthiness of the data. Researchers A and B coded the first, fifth, and ninth interviews independently. A discussion about codes lasted until consensus was made on all concepts. We also acknowledged and discussed our biases about body image and physical disability to help understand how they shape and influence the data. Triangulation of data (telephone interviews, one-on-one interviews, follow-up interviews, field notes) was used to converge information and multiple researchers worked together to apply their different perspectives to strengthen concepts (Carpenter & Suto, 2008).

## **Materials**

**LTPAQ-SCI telephone interview.** A 15-minute telephone interview using the LTPAQ-SCI (Martin Ginis, Hong Phang, Latimer, & Arbour-Nicitopoulos, 2012) was administered to gather information regarding participants' LTPA levels. Only information about LTPA (i.e., activity one chooses to do during free time) was requested.

This information was collected for purposes of the larger study, however, was particularly valuable for rapport building to increase quality of the interview data.

**Demographic information.** A fact sheet was used to gather general self-reported socio-demographic information about the participants. This data included information about age, gender, weight (if known), height (if known), ethnicity, age at the time of injury, level/severity of injury, and their American Spinal Injury Association (AIS) classification (if known).

### **Data Coding and Analysis**

In GT methodology, data collection and analysis are done simultaneously. One step of analysis was transcription of the interviews (converting oral conversation into written text), done verbatim immediately after each interview. Non-verbal information (e.g., silence and emotional cues, etc.), collected in field notes during the interviews, was embedded into the transcripts. Analysis of GT involves coding and organizing data. Charmaz (2006) describes three main coding processes: initial coding, focused coding, and axial coding. Initial coding is the first coding stage involving examining differences and similarities between events, actions and interactions. This was done line-by-line where codes were grouped together later into categories and given a name. Focused coding is the next step of analysis which is more conceptually involved. The codes are more directed, selective and conceptual than in initial coding and is completed iteratively by constantly comparing data with data, an integral component of GT analysis (Corbin & Strauss, 2008). According to Charmaz (2006) it is important to keep a memo of information throughout analysis to organize conceptual understandings, analytic examinations, and to record thoughts, questions and relationships between interviews.

The last stage of coding is axial coding and follows the development of a model where a core category is identified. Axial coding relates categories to subcategories, outlines the boundaries of a category and reassembles the data from initial coding to give coherence to the emerging analysis (Charmaz, 2006). The core category is represented in the preliminary model in Figure 1-1.

## **Results and Discussion**

Participants discussed the perceptual, cognitive, affective and behavioural aspects of their body image and described them all as influenced by their injury. This demonstrates the multidimensionality of body image and supports the importance of exploring body image experiences in people with SCI as their injury directly impacted their body image. Although this study was designed to explore body image experiences, an unanticipated finding was that participants consistently discussed engaging in specific self-presentational tactics to manage stigma related to their changed physical body since their injury.

A broad spectrum of body image experiences were reported among the participants (ranging from very negative to very positive). Generally, it was easier and more common for the majority of participants to discuss negative body image experiences. Therefore, for the purposes of this paper, findings are focused mainly on negative body image experiences and how self-presentation emerged as an important and related factor. The following main categories were found: appearance, weight concerns, negative functional aspects, impact of others, body disconnection, body nostalgia, drive for normalcy, hygiene and incontinence, physical activity, and self-presentation, all of which are delineated below. Since self-presentation (a construct related to but separate



from body image) emerged, the model represents more broadly body-related experiences. Therefore the relationships between the main categories are illustrated as a preliminary body-related experiences model in Figure 1-1.

### **Model Overview**

Depicted in the model (Figure 1-1) the core category appearance (and weight concerns) is illustrated in the centre of all other categories. This is because all surrounding categories are influenced by thoughts, feelings, and perceptions of appearance and weight. Encompassing the entire model is the category self-presentation as all body image experiences were related to self-presentational concerns or tactics. Then, the next layer moving outward from the core is negative functional aspects which emerged as another important component of body image experiences. The next two categories, bi-directionally related to appearance, weight concerns, and negative functional aspects, are body nostalgia and body disconnect. These relationships are bidirectional because appearance and weight concerns and negative functional aspects seemingly induced more body nostalgia and disconnect; as well, body nostalgia and disconnect perpetuated concerns about appearance, weight, and function. In the same layer are the categories impact of others and physical activity. The impact of others (e.g., social support) influenced both appearance and weight concerns as well as influenced motivation for physical activity. Physical activity has a bidirectional relationship with self-presentation because physical activity was discussed to induce self-presentational concerns and self-presentational concerns were also explained to endorse exercise behaviour. The next outer layer comprises the categories drive for normalcy and hygiene and incontinence which are all directly related to self-presentation.

## Appearance

As mentioned above, appearance emerged as the core category of body image experiences. Appearance was the most frequently and saliently discussed aspect of body image for participants and therefore seemed to represent body image experiences. In the model (Figure 1-1) the category appearance is circled by function. Although appearance distinctly represented body image, participants also discussed the importance of body function. Function was suggested to be a unique aspect of body image for someone who has a SCI (because function is lost and regained after a SCI) and is therefore included close to the core category.

Despite the reference to function, appearance was the centrefold of most discussions. In fact, there was sometimes a discrepancy between what participants would say was important to body image and what they would consistently discuss. For example, when asked what is most important to body image for someone who has a SCI, some participants would say function, however for the remainder of the interview they would focus on appearance and its importance. Therefore, appearance emerged as the core category of body image and will be the main focus of the findings. The following subcategories emerged within appearance: negative appearance features, standing, and their wheelchair. Negative functional aspects also emerged as an important aspect of the core category of body image and is also discussed below.

**Negative appearance features.** Many participants found it easy to list negative physical aspects of their body. The most frequently discussed negative features that were a direct result of SCI were the legs and stomach region. For Rebecca, she described her injury to directly affect every aspect of her body image. For example, she said,

It's [her injury] directly affected every single inch of my perception of my body, how I think about it... how I act towards it, how I feel about it... it's affected every inch because like I said before looks definitely meant something to me...

She described being very attractive before her injury (close to the cultural ideal), however since her injury she described trying to "salvage" her appearance. Rebecca underwent facial cosmetic reconstructive surgery as a result of her accident and therefore had additional struggles with accepting her appearance since her injury. She said, "When I see myself immediately it's, ok I see a girl who's been, unfortunately damaged who's now trying to salvage whatever she had before..." In fact, she had become very attached to the features that have not changed since her injury (e.g., her hair and nipples). Unfortunately, she explained most aspects of her appearance had changed for the worse, such as her back (due to rod placements eliminating her feminine curvature), stomach, legs, butt, and skin (due to rashes and pressure sores). For example, when she was asked if she could think of negative features of her body, she said,

Definitely! When it comes to posture and things like that when I'm sitting I always constantly look down [points at legs] I find that when I'm sitting or working out and things like that I notice I have more of a gut and that's more because I don't have abs or the abdominal muscles to be able to withhold or where organs show kind of thing, so gravity kinda just you know takes play and it looks like a gut... when I look down, which is a natural thing you do each day, I see that [her legs] and it's just one of those constant and immediate reminders that I have SCI...

Almost every participant described feeling insecure about his/her stomach due to a loss of abdominal musculature. This is consistent with findings in young men (Dewis, 1989) and women (Chau et al., 2008) with SCI who referred to this issue as 'quad belly'. Most of the women also discussed frustration with the fact their arms have become bulkier with muscle since their injury due to constant wheeling. This frustration stemmed from not being in line with the thin ideal as bulk is not found to be socially desirable in women. However, for the men, they were mostly satisfied with the size of their arms and shoulders because they were larger, consistent with the cultural male ideal. Therefore, it is interesting to note that the ideal did not change for the men or women in this study. Overall, participants found it easy to list negative appearance features of their body and disclosed their appearance to be directly affected by their injury.

**Standing.** Some participants discussed the importance of standing to their appearance. Rebecca explained standing was imperative in order for most clothes to look attractive. For example, she explained a time she went shopping for clothes at a mall,

... I thought it [going to malls] was the worst because there's mirrors everywhere and there's always clothes that you are like 'well I want to try that on, but that isn't going to look good when I am sitting down' and ... 'well that will look good on you' and I'm like 'yeah if I were standing up!' ... it's true, I've got to dress to how I look now and you know they always talk about dress to what your body type is, well my body type is someone sitting in a chair.

She also said,

So when things gather it all gathers at around my stomach well I want to make my stomach look good I gotta think of things that don't gather around here [points at

stomach] ... unfortunately it's always one of those things it's almost like someone who is on a diet you know they are like 'well maybe if I was 20 pounds smaller I would look at that or I'd be able to wear that'. I look at things and go 'if I was standing I would look really good in that but I'm sitting and that is not going to show off the same way... I know throughout the day there's always times where 'gosh! I'd look so much better if I were standing!

**Wheelchair.** Most participants considered their wheelchair to be an important aspect of their appearance. For example, this was the case for Mark as his wheelchair made a huge difference in how he felt about his appearance. He said, "... I've been feeling a lot better I've got a different chair... the chair you're in makes a huge difference in how you look at yourself because in my old chair I use to be slouching and now I look more upright and slimmer and like it makes such a difference." Since getting a new chair he felt better about his appearance. Rebecca explained a wheelchair to be her "ride", similar to that of a car. She said, "... looking at other people's wheelchairs and it's almost like someone else's ride you know kind of thing, but ultimately it's to make your body image look better." For Will, he mentioned the importance of being in a manual wheelchair as opposed to an electrical wheelchair. He said, "... my occupational therapist wanted to fit me for a power chair and I'm like 'well I don't really want to be in a power chair I want to use a manual chair because it looks cool...' Overall, participants explained their wheelchair to be an important aspect of their appearance and emphasized the importance of not having an electrical wheelchair as it would be a threat to their body image.

### **Weight Concerns**

Weight concerns were also discussed as central to body image experiences. As illustrated in the model (Figure 1-1), weight concerns represent the next layer after appearance. This is because weight concerns were found to be closely related to concerns of appearance (e.g., appearing slimmer in a chair) and were also the centre of concern for other experiences (e.g., body nostalgia, physical activity, drive for normalcy). Issues with weight resulted from major metabolism changes that occurred as a result of paralysis. Weight concerns emerged as its own distinct category because weight was not only related to appearance aspects but also other aspects of the body such as health, function, independence, accessibility, and hygiene. For Lizzy, weight concerns were a major issue in her body image. She was very preoccupied with her weight; for example, she said, "I mean, I'm aware that I've gained weight... it's something that I need to work on..." and "...I know I need to lose weight..." For Lizzy, weight was a topic that emerged frequently. This was also the case for Will, however he explained his concern with weight to stem from his wife who always pressured him to lose weight since his injury. Mark described most of his thoughts, feelings and perceptions about his body to be centred on weight. He said,

Well like I said I was really fit beforehand and like I enjoyed the way I looked before. Now, I can feel like I am overweight now still kind of working on that. That is like an ongoing thought. Basically, that is basically it. I feel like I am constantly overweight.

Some participants described a fear of gaining weight because that inevitably resulted in getting a larger wheelchair which can exacerbate issues of accessibility.

### **Negative Functional Aspects**

A category that emerged which seemed particularly important was negative functional aspects. This category is unique to someone who has a SCI because of the distinct physical changes that occur to the body resulting in some loss in function. In fact, Rebecca described her body to be "luggage" since her injury. Functionally, she described having to drag her legs around when she transfers. She said, "... It's [her body] is my luggage now. When I'm having to transfer in and out of wheelchairs I see my legs it's not you my legs look like its more 'ok I gotta drag my legs over' they are more like luggage".

Negative functional experiences were particularly salient acutely after injury. For example, Mark said, "It was just scary. Everything like nothing moves nothing is moving my fingers were dead like couldn't move my hands I was upset it's because it's just upsetting really". The loss and some regain of function is a unique experience of SCI and therefore played a significant role with other surrounding body image categories in the model (Figure 1-1).

### **Body Nostalgia**

Almost every participant had nostalgic thoughts about his/her body from before their injury. Primarily they were nostalgic about their appearance (and weight), but some also mentioned being nostalgic about their body function. Depicted in the model (Figure 1-1), body nostalgia emerged as the next category closely positioned with appearance and weight concerns. This is because nostalgic thoughts often centered on appearance and weight. Furthermore, the relationship between these categories is bidirectional as nostalgia resulted in more weight and appearance concerns.

One way participants demonstrated body nostalgia was by glorifying their body before their injury. Many participants considered their body pre-injury to be very close to

the Western-cultural ideal. In fact, when asked what their ideal body is now, many suggested their body before their injury. For example, Will said, "No, I was the ideal" and when he was asked to explain what the ideal body looks like, he described his appearance the same way he described his body before his injury. Samantha also believed herself to be close to the ideal before her injury. She explained, "... well I am 5'9 so I'm quite tall and I was probably 120 pounds I was thin and tall and blonde and you know could turn a few heads kind of thing... I guess I was pretty hot haha..." Caroline was nostalgic about her appearance before her injury and mentioned on several occasions that she wanted to show a picture of herself before her injury to demonstrate how attractive she was. Rebecca conveyed the most nostalgic thoughts about her body from before her injury. She too explained her appearance to be very close to the ideal and found herself constantly thinking back to how her body used to appear. For example, she ruminates about certain body features, she said,

I was so upset because I was actually very, very happy with my chest size before my accident and was I guess one of those features that I really, really liked beforehand and now I'm kinda, I still again I'm always looking back and I'm like 'I wish they were the size they were...'

Overall, body nostalgia was represented by participants persistently fantasizing about their body before their injury. Many wished and wanted their 'old' body back and often glorified what their body used to look like, explaining it to be very similar to the cultural ideal.

### **Body Disconnection**



This category emerged as some participants seemingly had a dualistic or disconnected view of their body. In the model (Figure 1-1) body disconnection is also displayed close to the core category appearance, because negative thoughts, feelings, and perceptions of appearance led to a more disconnected view of the body. This relationship is bidirectional as body disconnection also facilitated additional appearance discontent. Body disconnection was explained as physical, emotional, or perceptual. Physically, participants discussed not wanting to touch their lower body. Emotionally and perceptually, participants described the body to be a machine (e.g., car analogy), would feel desensitized to private aspects of their body, or would never want to see their lower body in a full-length mirror. The most profound disconnection was described between the mobile and immobile aspects of the body. For example, Mark blatantly said body image did not apply to his legs because they are immobile. He said, "I can't really say much about my lower body, I dunno, because it's immobile. It's not like I can be like 'look at my legs' so like body image doesn't really apply to my lower body." Samantha also demonstrated a disconnection with her body, she said,

It's funny because I often think about my body I think about two separate bodies... sometimes when I refer to my legs it's almost like a different part of my body or like my stomach or the parts that I can't move or don't work properly I almost think of as like a separate entity

Another form of disconnection was depicted by participants who referred to their body as a machine, as if the body was a separate entity from the mind. For example, Larry often used a car analogy to explain a disconnection he felt to his least functional leg. For example, he said,

... it's [his body] a machine and if it's not working or if I have a useless part on the machine I don't need it then why drag it around I look at it as though you know roof rack on a car if you aren't using a roof rack and it's not doing anything for you if it's not helping you out or anything then get rid of it. Why keep it?

Larry also explained to have an emotional disconnection to his legs, particularly the leg that has the least function. He said,

I don't have an emotional connection to my body. The left leg as I mentioned before has different movement from the left to the right and my left leg is almost useless... I went to the doctor and I asked him if he would cut it off at the knee because it is useless. It's bothering me, it's dragging me down, it's slowing me down... I have no emotional connection to that part of my body...

Star constantly told herself, "... I am not my body..." as a way to cope with some of the drastic changes her body has undergone since her injury. For Rebecca, she explained a disconnection from her body and believed it to stem from experiences during hospitalization immediately after her injury. Treatment from medical staff caused her to be desensitized to private aspects of her body. She explained feeling as though her "temple" is gone. She also felt degraded and scrutinized medically. Her body was treated as a damaged object that needed to be cured. In a study by Chau and colleagues (2008), participants with SCI reported a similar dichotomy between the mind and the body. Their bodies were treated as objects by medical professionals and they were classified by their disability which perpetuated negative feelings and a disconnection to their body. Lastly, Lizzy described wanting nothing to do with her lower body, emotionally, perceptually, and physically. Emotionally and perceptually, she never wanted to view them in a mirror,

as that would bring about negative emotions about her body. Physically, she would not touch them, because to her it felt weird touching something on her body that has no sensation. A similar disconnection has been reported in previous research conducted by Potgieter and Khan (2005) who found participants in their study would have positive perceptions towards their face, however very negative perceptions towards the rest of their body. For example, participants in their study would discuss never looking at their body in a mirror, only their face. The tendency to 'split face' has been conceptualized as a way of disowning a defective aspect of the body which is believed to impede self-acceptance in people with physical disability (Wright, 1983). This tendency was described by participants in this study. For example, Lizzy explained never looking at her body in the mirror - rather, she would look at only her face.

### **Impact of Others**

Every participant explained that other people in their lives impacted their body image. Examples of other people who impacted body image experiences include: family members, significant life partners, medical staff, and friends. Impact of others is illustrated in the model (Figure 1-1) as the next layer of experiences between the core category and physical activity. This impact can be organized by the following subcategories: attention from the opposite sex and social support. Attention from the opposite sex very much influenced appearance and weight related concerns and social support influenced involvement in physical activity.

**Attention from the opposite sex.** Every female participant described a need to have attention from men in order to feel attractive. For example, Rebecca relies on the reassurance of men to feel physically attractive. She said, "... especially guys obviously

when they compliment, my mom can say I look nice but then it's like ok but you're my mom..." Rebecca explained the need to receive compliments from guys in order to feel attractive, as though compliments from other people such as her family are not valid. She said,

... I am very much a person that my best friend could say I look good and I won't think it unless a boy says I look good so I very much need the reassurance from a male companion or the affection of a male, of boys, to get, to reassure me that I 'oh yeah ok I do look good'.

Star shared a similar opinion about receiving appearance commentary from others. When she receives a compliment about her appearance from another woman, she automatically discredits it, however, the opposite is true if the compliment is from a man. It is interesting to note this tendency was described by only the women in this study, not the men.

**Social support.** Many different sources of social support were provided to participants in this study. For example, a partner, family members, friends, medical staff, people from peer support programs, and people through exercise lab facilities all provided social support. Many participants discussed that social support (or lack thereof) influenced body image experiences. Danny explained having a strong social support network helped him adjust to his body and understand his body function. His family and friends also encouraged him to engage in healthy activities such as exercise. For example, he said,

I had a really good support system... from the very beginning she [his mom] was in the hospital with me learning how to do things... motivating me to keep going...

when I got back into high school a friend would help me do workouts during lunch times or whenever he had a spare he helped a lot through high school... my mom being there again with workouts and my brother also, my sister, learning about my spasms...

For Danny, his strong social support network was important in his involvement in physical activity. However, not every participant had social support, particularly during the adjustment period. For example, Star explained having no support during her adjustment and she explained having much more negative body image experiences. Therefore, the impact of others seemed to be directly related to body image experiences as well as the involvement in health activities such as exercise.

### **Physical Activity**

There was a broad range of physical activity levels among the participants. The model (Figure 1-1) illustrates physical activity to be closely related to self-presentation. This is because some participants had a need to be perceived as physically active in order to reduce stigma (e.g., being perceived as incompetent, dependent). The main motivating factors to exercise were for functional (i.e., improvements in strength) and social benefits. For Will, he mainly enjoyed the social aspect of exercise labs designed for people with SCI and does not enjoy the structured exercise routine atmosphere. Social benefits of exercise were described to promote acceptance of the body (thereby improving body image). Second to functional and social benefits to exercise are improvements to appearance. Interestingly, previous research found appearance satisfaction to be unrelated to leisure physical activity levels in women (Bassett et al., 2009) or men with SCI (Bassett & Martin Ginis, 2009). Perhaps people with SCI are more motivated for

functional and social benefits of exercise than for appearance reasons. Regardless, participants discussed physical activity to be influenced by other people, such as family, friends, and significant partners. Mark explained his girlfriend played an important role in his physical activity. He said, "[His girlfriend] has been helping me a bit, so my girlfriend has been helping me a lot because she helps me workout and stuff like that."

### **Drive for Normalcy**

Many participants discussed a strong motivation or need to be 'normal'. This category, as depicted in the model (Figure 1-1), is linked to self-presentation because participants who demonstrated a drive for normalcy were preoccupied with appearing 'normal' in others' eyes (as well as their own). Furthermore, greater self-presentational concerns (e.g., derived from being surrounded by able-bodied peers) seemed to produce a greater drive for normalcy as demonstrated through a bidirectional relationship. For example, Rebecca was very consciously aware of how her body appeared to others and would engage in tactics to appear more 'normal'. For example, she said, "... I'm again more conscious about 'oh my God are my feet together or not together or sloppy or do I look a little bit more disabled than I am?' Because being disabled, there's different degrees of being disabled..." Star described a need to 'blend in the crowd' and a need to normalize. She said,

... I mean we come from this dominant culture of able-bodiness so you know we even as people with disabilities try to normalize as much as possible so I know even with this you know we are girls with SCI sometimes we don't like to associate too much with each other because we want to be more normal...

This statement made by Star is particularly compelling. It seems that the cultural standard to look 'normal' can be so powerful that some people with a physical disability may not even associate with others who have a disability in fear it will threaten their desire to be perceived as 'normal'. "Normalizing" the body through strategies of covering up visible disabilities and enhancing other aspects enables the creation of a self-concept that is not solely based on one's disability. In efforts to preserve a favourable image, people with SCI have been found to focus on efforts to appear as similar to the able-bodied community as possible (Dewis, 1989).

### **Hygiene and Incontinence**

One important aspect of normalcy was feeling clean. One threat to this need was incontinence, thus, hygiene and incontinence are linked to drive for normalcy because smelling of urine or feces was a reminder of not being 'normal'. Therefore, drive for normalcy, hygiene and incontinence are all conceptually related, as illustrated in the model (Figure 1-1) and in-turn influenced self-presentation (e.g., tactics to conceal incontinence). Rebecca explained that her insecurities with her body changed since her injury. She said, "Insecurity is way up there as opposed to beforehand, like I was insecure about normal female issues, now my insecurities are more like wondering what they are thinking and wondering what if I have an accident kind of thing..." Two subcategories were found for hygiene and incontinence: aesthetic reasons and health reasons.

**Aesthetic reasons.** Aesthetically it was important for participants to smell clean as there was an inherent fear of smelling, particularly of urine. This was salient acutely after injury when participants had very little control of their body function. For example, when Rebecca was asked what is the most important thing for body image immediately

after an injury, she said, "Feeling clean! Feeling clean because ultimately after a SCI, you can't shower and you can't do anything except bed baths..." Rebecca explained being able to have a shower again as one of the best times after her injury in terms of body image. She said, "... 'oh my gosh I get to feel clean!' like how I would normally feel before the accident, like you know an actual shower..." She also shared a fear of smelling of urine. For example, she said,

"... I always wanted to make sure I smelt good, not like wearing perfume, but like 'mom, do I smell like urine?' Do I smell, do I smell like I need to have a bath?' kind of thing, make sure I always smelt good..."

Danny was the only participant who used a leg bag to contain his urine. He explained his leg bag to negatively influence his body image. He was preoccupied with thoughts of whether it was visible to other people or if it made him smell unclean. For example, he said,

... you have to make sure that the leg bag doesn't get too full, you have to watch how much you have to drink because again you have to go to the washroom... you have to be careful with what you wear so that it doesn't kink anything in your tubing... you know the odour... you have to keep check on that at all times... sometimes your tube gets caught up on your leg and then that makes a mess and then that gets all over your pants and then you stink like piss and then it's like 'oh well now that I stink like piss I don't want to be here anymore!' and embarrass myself in that aspect...



For Danny, his leg bag was a constant reminder that he had a disability which was not socially desirable and would therefore engage in self-presentational tactics (e.g., the use of clothing) to conceal his leg bag.

**Health reasons.** Some participants had a need to be clean in order to prevent infections. If participants did not maintain a high level of hygiene, secondary complications such as urinary tract infections were exacerbated. The constant susceptibility to infection was also a psychological reminder of not being 'normal'. Therefore, participants were motivated to remain hygienic. Samantha explained proper hygiene to be a fundamental aspect of taking care of yourself after a SCI. She said,

"I think it's important that people take care of themselves like you I mean this sounds so basic but that you shower and you do proper grooming techniques and that you do take care of yourself because I play wheelchair basketball and there are a few people on our team who do not it's so unfortunate I mean you could look so much better or smell better you have to take care of yourself and all your body issues and stuff like that is really important to maintain that sense of well-being and being clean is all important.

### **Self-Presentation**

Most participants explained having some sort of self-presentational concerns or engaging in tactics to maintain a certain image to others that was important (e.g., being perceived as 'normal' or independent). Although intuitively it is not surprising this category emerged since people with SCI experience stigma which thereby may induce self-presentational tactics to overcome stigma, this category still emerged unexpectedly. In fact, participants disclosed self-presentational experiences independently as none of

the original interview questions probed about self-presentation directly. Self-presentation developed as an over-encompassing category, as depicted in the model (Figure 1-1) circling all other categories, and related directly to body image experiences. Two subcategories were found to emerge: physical attractiveness and attributive tactics.

**Physical attractiveness.** Many participants, particularly the women, were preoccupied with ways to enhance physical features to be perceived as more attractive (particularly by men). Therefore, the main motivation behind the goal of being found physically attractive was to gain status and social desirability in order to attract a member of the opposite sex. Some methods used by participants included being fashion conscious, wearing make-up and jewellery, as well as using clothing to hide or accentuate certain features. Samantha even went to the extreme of getting cosmetic enhancement (breast augmentation) since her injury. Enhancing appearance seemed to be a method of compensating for the physical disability. Women and men must contend with Westernized gender roles and body ideals that are constantly imposed upon them. For women, this has been described as a "double impediment" (Henderson, Bedini, & Hecht, 1994) as they face discrimination from being a woman as well as having a disability. Most of the women in this study had an inherent fear immediately after their injury of not being found attractive by men ever again. For example, Samantha explained the adjustment period to be a time filled with many negative thoughts. She said, "I was like 'what man would ever want me, how am I going to get a boyfriend' you know, I am all disfigured..." Clothing was the main method described to enhance or conceal certain features. Clothing was particularly important for concealing the stomach region (one of the most insecure features discussed by participants).

Participants also discussed concealing their legs due to insecurity about atrophy. For the women, this entailed never wearing skirts or dresses. The men also described their legs to be flawed from atrophy since their injury and believed it to be a marker of disability which was not favourable to their social image. In sum, certain tactics (wearing make-up, use of clothing, and cosmetic surgery) were used in order for participants to appear more attractive in hopes to be found socially desirable to the opposite sex.

**Attributive tactics.** Participants would describe engaging in certain behaviours or tactics in order to be perceived contrary to the stereotypes associated with SCI. For example, Rebecca described displaying her body in a certain way in order to look "less disabled". She also explained trying to give the impression that she is confident, although she explained truly having very low self-confidence. She said,

... I portray myself as, as someone in a wheelchair and I'm meaning I am referring to body image in terms I don't slump you know, chest out, I hold my hands a certain way that I know looks flattering as opposed to doing something that is not very attractive and so I make sure I cross my legs whenever I can because I know it looks more prettier and I look more dainty.

For Lizzy, it was important that she was perceived by other people as independent. For example, when she was asked what matters the most for body image she said,

I guess the perception that I, not to say I don't care what people think, but I don't want people to think that I don't know how to take care of myself or that because I'm in a wheelchair I don't care what I look like, I guess maybe that is the biggest thing...

Rebecca said it is important to her to be perceived as physically active. For example, she said, "I am going out for a hand cycle ride and I am being active and people are like 'wow! That's an active wheelchair person' and I'm just like 'yeah!' and I feel pumped about myself..." Samantha shared a similar concern. She did not want to be perceived as lazy so she would remain active by exercising and being involved in sports. Overall, since people who have a SCI are considered an 'other' group from the dominant able-bodied culture, it seems intuitive that embedded in some of their body image experiences would be attributive tactics to help lessen stigmatized experiences such as not being found desirable by the opposite sex.

Caroline also described the need to be perceived as capable of taking care of herself. She said, "... I'm clean that I present myself well and that's not to me like a certain sort of way just that I am capable of taking care of myself just like anybody can take care of themselves..." She discussed the many efforts she would take to camouflage that she had a bladder or bowel accident. She described always having extra clothes and pads with her in case of an accident in an effort to prevent other people from knowing and thereby thinking she is incompetent. Such strategies have also been reported in other men with SCI who try to camouflage incontinence in an attempt to normalize (Dewis, 1989).

Overall, participants would regularly engage in self-presentational tactics (e.g., showering and concealing a leg bag) in order to preserve social desirability. This has been found to be a positive effect of self-presentation as a desire to avoid negative implications of poor hygiene prompts more attentive self-care (Price, 1990), which can prevent further complications such as urinary tract infections. On the contrary,

incontinence arouses intense concern regarding one's public impression because of the associated inferences that others may draw about one's competence. Some people with urinary incontinence decide to withdraw from social life all together rather than risk consequences and embarrassment (Fonda, Woodward, D'Astoli, & Chin, 1995). This can have serious implications, particularly for people with SCI who may experience both bowel and urinary incontinence, either of which can be publicly humiliating. For example, because of embarrassment one may choose to avoid exercise settings (as exercise may induce incontinence) and therefore live a sedentary lifestyle. However, physical activity has been found to largely benefit many aspects of health for people with SCI (e.g., cardiovascular health and longevity; Nooijen et al., 2012). Therefore, the predicament between self-presentational concerns of incontinence and the need to acquire health benefits from exercise may be particularly problematic for people with SCI.

### **Conclusion and Implications**

Participants described their injuries to directly affect all dimensions (perceptual, cognitive, affective, and behavioural) of their body image. Therefore, body image played a significant role in the experiences of having a SCI for the participants in this study. Furthermore, most participants had self-presentational concerns and engaged in attributive tactics as a means to reduce stigma. It is important to note the strength of employing a GT methodology in this study as it allowed for a completely inductive emergence of the unexpected category self-presentation. This demonstrates the strength of qualitative designs as more stories have the chance to emerge - some of which may be missed if only quantitative methods are employed. Therefore, GT methodologies may inherently expose unexpected avenues for future research.

Body image was represented by appearance for participants in this study. This was due to most participants predominately discussing appearance aspects of their body image. However, interestingly there was clear ambivalence between what participants believed should be important to their body image (i.e., function) and what they actually spent time discussing (i.e., appearance). Therefore, appearance was found to be the core category, followed by weight concerns, negative functional aspects, body nostalgia, body disconnection, impact of others, physical activity, drive for normalcy, hygiene and incontinence, and self-presentational concerns.

Participants were found to have distinct self-presentational concerns which related to all body image experiences depicted in the model (Figure 1-1). For example, many participants disclosed a need to be perceived as 'normal' in an able-bodied dominated society. This need led to a drive for normalcy, similar to the drive for thinness or drive for muscularity found in non-SCI samples. Participants who shared a drive for normalcy demonstrated having a cognitive schema which associates being 'normal' with socially desirable characteristics (e.g., power, social status and desirability). This then led some participants to engage in certain tactics (e.g., withdrawing or engaging in physical activity, concealing of body attributes), in pursuit of attaining the ideal image of being 'normal'. In fact, many participants explained an able-body or the body they had before their injury to be their ideal - an undoubtedly impossible goal and therefore problematic to body image experiences as this discrepancy may lead to increased body dissatisfaction and decreased body-esteem as has been found in non-SCI samples (e.g., Bessenoff & Snow, 2006).

Self-presentation has been documented to have both positive and negative influences on health behaviour (e.g., Martin, Leary, & Rejeski, 2000). For instance, as discussed by participants in this study, self-presentational concerns (e.g., incontinence) were found to hinder physical activity whereas other concerns (e.g., being perceived as active and competent) encouraged activity involvement. This can have serious implications for people with SCI as physical activity has been well documented to improve cardiovascular health (a common cause of morbidity and mortality in this population; e.g., Nooijen et al., 2012), function, independence, and overall quality-of-life (Hicks et al., 2003). Implications of these self-presentational concerns may extend to hospital, rehabilitation, and exercise lab settings to improve care administered to people with SCI. For example, as explained by participants in this study, some body image concerns stemmed from treatment during hospitalization (i.e., medical scrutiny) and continued throughout treatment in rehabilitation. Furthermore, exercise lab settings may produce self-presentational concerns among clients as they may have inherent worries of incontinence. This may be problematic since physical activity has been well documented as a significant contributor to health and quality-of-life for people with SCI (e.g., Hicks et al., 2003) and therefore involvement in activity is critical. A concrete recommendation for medical and rehabilitation staff would be to encourage and promote the importance of social support. Every participant noted that his/her body image was impacted by others, one of such impacts being positive social support in hospital, rehabilitation, and exercise settings by the staff or family members. Since staff have the potential to be a positive influence on body image thereby encouraging health-enhancing behaviours, seminar

series should be held to educate medical professionals the importance of social support for people with SCI.

### **Limitations and Future Directions**

This study was designed as a pilot to explore what body image represents for someone with a SCI. This study used a modified GT methodology thus a preliminary model was derived. Findings are introductory in nature and the design was intended for exploratory purposes. As well, due to the qualitative nature and small sample size, findings are representative of this sample only; therefore conclusions and the use of the current model may not be applicable to everyone who has a SCI. For example, participants in this study had an overall high level of function, independence, and physical activity. In addition, there were more women than men in this study which may not reflect current gender demographics of people with SCI.

Future research should continue to investigate body image in those with SCI to develop a substantive theory about body image experiences and self-presentation for people with SCI or other physical disabilities. Furthermore, this study opens avenues in research to explore quantitatively how body image and self-presentational concerns or tactics impact exercise adherence, well-being or quality-of-life for those living with a SCI.



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Table 1-1

*Participant Characteristics*

Participant	Age	Gender	Age at Injury	Level of Injury	Severity	AIS Classification	Years Post-Injury	Height (feet)	Weight (lbs)	LTPA
1. Rebecca	26	Female	21	T6	Complete	A	5 years	5'7"	110	2/180 mins
2. Samantha	32	Female	18	T1	Complete	A	14 years	5'9"	140	3/60 mins
3. Will	42	Male	38	C6/C7	Incomplete	B	4 years	5'11"	260	3/120 mins
4. Lizzy	44	Female	34	T7	Complete	A	10 years	5'4"	unknown	0
5. Mark	21	Male	17	C7	Incomplete	B	4 years	5'8"	190	3/30 mins
6. Larry	48	Male	39	C3	Incomplete	D	9 years	5'11"	180	1/120 mins
7. Caroline	63	Female	27	C3/C4/C5	Incomplete	D	36 years	6'2"	214	2/60 mins
8. Star	36	Female	18	T3	Complete	A	18 years	5'4"	121	2/60 mins
9. Danny	35	Male	19	C5	Incomplete	C	16 years	5'9"	215	0

*Note.* LTPA scores based on self-reported number of days in the last 7 days participants took part in moderate to vigorous intensity leisure activity and amount of consecutive minutes they engaged in that activity. Recommendations are at least 20 minutes of moderate to vigorous activity for 2 times a week of aerobic and strength training activities.

Table 1-2

*Interview Questions*

- 
1. Can you tell me a bit about how you view your body?
  2. Tell me about how you first adjusted to your body after your injury?
  3. Describe your experience during rehabilitation immediately after your injury with regards to how you felt about your body?
  4. Will you talk about how you see and think about your body now?
    - a. How about before your injury?
    - b. How about acutely after your injury?
  5. Overall, how do you feel about your body now?
    - a. How about before your injury?
    - b. How about acutely after your injury?
  6. In what ways do you act towards your body?
    - a. How about before your injury?
    - b. How about acutely after your injury?
  6. Tell me about how people in your life (partners, family, friends) affect your body image.
  7. What matters the most in regards to body image for someone who has a SCI?
  8. What do you consider to be the ideal body?
  9. What do you think having a negative body image means?
  10. Is there anything else that you feel is important when it comes to body image, especially for someone with a SCI?
-

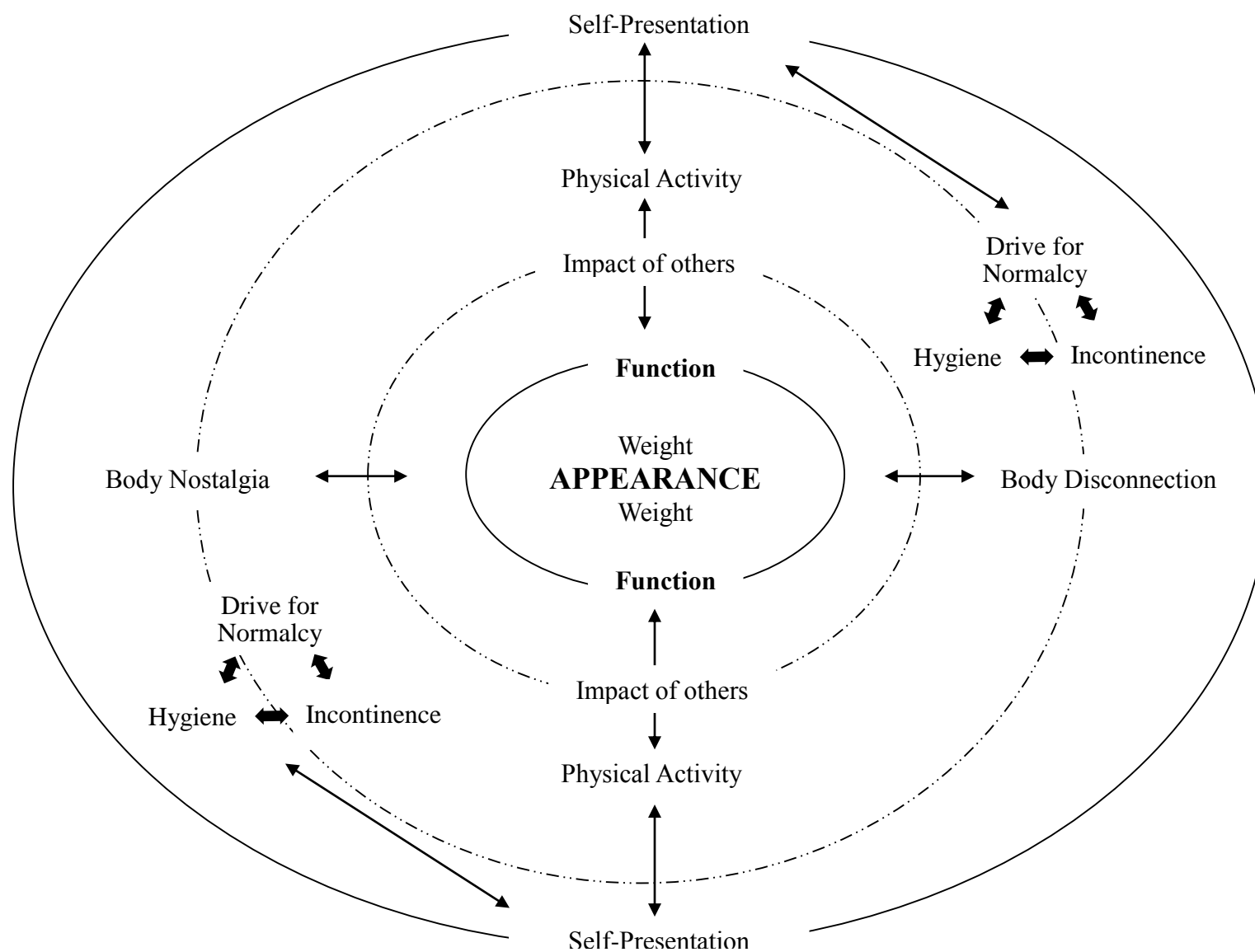


Figure 1-1. Preliminary body-related experiences model for people with SCI



## **Article 2: "It's all about acceptance": A Pilot Study Exploring a Model of Positive Body Image for People with Spinal Cord Injury**

Body image is a multidimensional concept which reflects how we see, think, feel and act toward our bodies (Cash & Pruzinsky, 2002; Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). These perceptions, thoughts, feelings, and behaviours can be positive or negative in nature and affect many aspects of psychosocial well-being and quality-of-life (Cash & Smolak, 2011). The focus in body image research has been primarily on eating pathology and weight and shape concerns among White female college and adolescent students. Regardless of some diversity in the literature (e.g., drive for muscularity in men; McCreary, 2011), the research is still presently centred on adolescent and college women's body image experiences, which has been recognized as a major limitation by experts in the field (e.g., Cash & Smolak, 2011).

Much of the theory, research, and practice in body image has focused largely on the improvement, prevention and treatment of negative body image outcomes. Researchers have argued that by only deconstructing negative body image there is insufficient understanding of body image and psychological health. Positive body image has often been conceptualized as deriving from the absence of negative body image characteristics. This portrayal of positive body image is incomplete since the absence of pathology does not always equate health. As stated by Keyes and Lopez (2002) "mental health is not merely the absence of mental illness" (p. 48). Using cluster analysis, Williams, Cash, and Santos (2004) revealed that positive body image is quantitatively different from negative body image. They uncovered three distinct groups of women and body image: (1) women with positive body image, (2) women with normative body

image discontent, and (3) women with negative body image. This supports the notion that positive body image is not merely the opposite of negative body image.

In an attempt to understand positive body image, a handful of studies across different age groups and geographical locations have been conducted. Tylka (2011) synthesized findings from studies of positive body image (e.g., Avalos, Tylka, & Wood-Barcalow, 2005; Frisen & Holmqvist, 2010; Homan & Boyatzis, 2010; Wood-Barcalow, Tylka, & Augustus-Horvath, 2010) and found similar characteristics emerged across the different samples. Two core characteristics were identified: (1) body appreciation (appreciating all aspects of the body including functionality and health and not solely appearance) and (2) body acceptance and love (accepting the body regardless of not being completely satisfied with all aspects). In addition to these core characteristics, Tylka (2011) also identified five characteristics that help promote and maintain positive body image: (3) broadly conceptualizing beauty (believing a variety of body shapes and sizes are beautiful); (4) media literacy (understanding of the fabricated nature of the media); (5) perceiving unconditional acceptance from others (for qualities other than appearance); (6) finding others with a positive body image; and (7) being spiritual or religious (perceiving a higher being has designed everyone to be unique). The last characteristics are thought to emerge from positive body image: (8) inner positivity influencing outer demeanour (refers to believing inner qualities shine through outer appearance) and (9) listening to and taking care of the body. For instance, those with positive body image engage in positive behaviours and activities for intrinsic rewards and health benefits (e.g., exercise for stress relief). Based on these characteristics, positive body image can be understood as overall love and respect for the body. It provides a

positive schema in which incoming positive information is internalized and incoming negative information is quickly rejected or reframed. This includes acceptance of the body and not internalizing cultural ideals (Wood-Barcalow et al., 2010). Positive body image does not mean someone thinks his or her body is perfect and physically attractive in line with the cultural 'ideal'. Rather, anyone (e.g., those who are overweight, from varying cultural backgrounds, or who have a physical disability) can have positive experiences with the body (Tylka, 2011).

A limitation in the positive body image literature is a lack of research on individuals with physical disabilities as most research has focused on able-bodied college and adolescent students (e.g., Frisen & Holmqvist, 2010; Wood-Barcalow et al., 2010). In fact, Wood-Barcalow and colleagues (2010) called for additional studies in positive body image in diverse samples to contribute to the theory of positive body image. Many of the same characteristics synthesized by Tylka (2011) from previous research that promote, maintain, or contribute to positive body image may apply to people with physical disability (e.g., a spinal cord injury; SCI), or, there may be very distinct differences in characteristics of positive body image.

A SCI results in immediate physical impairments consequently resulting in a changed body. Such changes include changes to appearance, functionality, and independence (e.g., Galvin, 2005). Many SCIs occur as a result of trauma to the vertebral column (Somers, 2010). This impairment affects several body functions including, for example, mobility, sensation, regulation of body temperature, and bladder and bowel function. Impairment to body sensations and functions may in turn influence experiences of embodiment (body awareness and responsiveness; e.g., Arzy, Overney, Landis, &

Blanke, 2006). These changes that occur to the body also move it away from the Western culture ideal body type. Therefore, body image may be particularly important for those who have a SCI as it may be related to overall well-being (e.g., Chau et al., 2008; Taleporos & McCabe, 2002).

Most research in SCI and body image has investigated the negative implications, such as struggles with conformity to masculine gender roles, changes to sexual self-esteem and negative changes to overall functionality (e.g., Burns, Hough, Boyd, & Hill, 2010; Potgieter & Khan, 2005). However, one study by Bassett and Martin Ginis (2009) looked at body image (satisfaction with appearance and functionality) among men with SCI. Results indicated the men were generally satisfied with their appearance and function (levels similar to the general population) demonstrating that people with a physical disability do not necessarily have increased body dissatisfaction. Another study by Bassett, Martin Ginis, and Buchholz (2009) investigated women with SCI and their body image. This pilot study demonstrated that women in their study were slightly dissatisfied with their appearance and slightly satisfied with their function. Appearance satisfaction was found among the women with a smaller waist circumference, a lower percent body fat, and greater years post-injury while functional satisfaction was highest among the women with greater years post-injury. This study demonstrates that body image may improve among individuals with a SCI as they become more adjusted to their injury and are further post-injury. Therefore, there is some evidence of positive body image in people with SCI.

Overall, the current study was designed to address two main limitations in the body image literature: (1) the limited research on positive body image; and (2) the lack of

positive body image research outside adolescent or college student samples. Therefore, the purpose of this pilot study was to explore positive body image experiences among people with SCI. The following theoretical questions were investigated:

1. Do people with SCI experience positive body image and if so, how is it represented?
2. Are there similarities in positive body image characteristics in people with SCI as those found in able-bodied individuals?
3. Are there unique characteristics related to positive body image for people with SCI?

## **Method**

### **Participants**

Nine participants from southern Ontario who had a SCI were recruited for this study (five women, four men). To the researchers' knowledge this is one of the first studies in the area, therefore a flexible inclusion criteria was implemented. Participants were included if they met the following criteria: 18 years or older, at least 12 months post-injury, and no history of a clinical eating disorder. Those who had a history of an eating disorder could not be included due to the fact they may have a much more extreme body image (e.g., disturbances). Participant characteristics can be found in Table 2-1. All names are presented as pseudonyms for confidentiality purposes. Although geographically and culturally this sample was homogenous (predominately Caucasian residing in the Niagara Region), there was much variability in participant characteristics (e.g., age, gender, level of injury, severity of injury, physical activity level).

### **Research Team**

The research team comprised four individuals (all Caucasian), all of whom had varying levels of educational background and research experience. All members of the

research team were part of the development of the interview guide and over-arching concepts of the data. The primary researcher, researcher A (first author), was a 25-year old female Master's student. She was 162 cm tall, weighed 123 lbs (body mass index = 21.30), and had a petite build. She was a novice researcher in the area of body image and SCI. She developed the research idea, conducted the project, and transcribed and analyzed 100% of the data. At the time of the study, researcher B (42 years of age) had extensive research experience in the area of body image and self-presentational concerns across the lifespan. Her experience includes investigating the impact of body image and self-presentation on psychological states and health behaviours, using both quantitative and qualitative approaches. She coded and analyzed 30% of the data and played a major role in the refinement of concepts, categories and subcategories emerged from the data. Researcher C (43 years of age) had extensive experience in qualitative methodologies and played a major role in guiding the rigour of the research design. Lastly, researcher D (42 years of age) had extensive expertise in the area of SCI. He was the director of the Neuromuscular Rehabilitation Lab at the university and was involved in recruitment of participants.

### **Study Design**

A modified constructivist grounded theory (GT) was employed for the current project. Constructivist GT is a much newer approach to GT than the more traditional ones designed by Glaser and Strauss. Constructivist grounded theorists take on a reflexive stance toward their research process and explicitly assume an interpretative view (i.e., multiple realities exist) and that any analysis is contextually situated in time, place, culture, and situation (Charmaz, 2006). When grappling with the social construction of

body image and disability, it is imperative to have an interpretive view to truly understand the meaning behind the subjective experiences of embodiment. The reality and experiences of the body for someone with a SCI may be much different than for an able-bodied researcher. This GT study was modified by having fewer interviews as opposed to traditional GT studies which comprise of up to 30 to 40 interviews. Since this was a pilot study and was one of the first to explore positive body image in people with SCI, a modified GT was implemented for exploratory purposes. Modified GT has been successfully conducted and suggested by past researchers (e.g., Cutcliffe, 2005; Kearney, Murphy, & Rosenbaum, 1994). This approach remains rigorous with the ultimate goal to develop a preliminary model. Our preliminary model was generated inductively through an iterative process through which new data was constantly compared to emerging codes, categories, and concepts (Charmaz, 2006). All information was conceptually linked together to form a preliminary positive body image model for people with SCI (Figure 2-1).

## **Procedure**

Data was collected as part of a larger study exploring overall body image experiences (e.g., negative body image) and physical activity in people with SCI. Upon university research ethics clearance (see Appendix A), participants were recruited using purposive sampling procedures known as snowballing (Patton, 2002). Initial participants were recruited by Researcher D (through the exercise lab facility associated through the university) and then interested participants were asked if they knew others who may be interested in participating who fit the inclusion criteria. Once participants displayed interest in the study, they were emailed a letter of invitation (see Appendix B) outlining

details of the project, the Leisure Time Physical Activity Questionnaire for People with SCI (LTPAQ-SCI; see Appendix C), and the one-on-one interview guide (see Table 2-2 and Appendix D). Then, participants were scheduled for a telephone and an in-person interview. Telephone interviews (approximately 15 minutes) were completed first and participants provided verbal informed consent.

A common method used in GT research is in-depth interviews. In cases of sensitive subject matter, individual in-depth interviews provide an effective tool to create an environment where participants would be likely to speak more openly (Liamputtong, 2009). For the purpose of this project, interviews were semi-structured allowing the flow to be determined by the participant and the researcher to explore unexpected material that arose (Patton, 2002). The interview guide was developed based on previous interview guides used for understanding positive body image developed by past researchers (e.g., Frisen & Holmvist, 2010; Wood-Barcalow et al., 2010). Interview questions were also developed using the definition of body image, whereby the four components were broken down into questions (e.g., how do you see your body in a positive way?). Interviews took place on the university campus in a private office or at the participant's own home. On arrival to the one-on-one interview, participants provided written informed consent (see Appendix E) and completed general demographic information (see Appendix F). The one-on-one interviews ranged from 60 minutes to 2 hours in length and participants were offered a break midway through the interview. A few weeks later two participants (Caroline and Danny) who seemingly had a positive body image were recruited to do a follow-up interview to elaborate on specific concepts. Follow-up interviews lasted about



60 minutes. All interviews were audio recorded for transcription purposes and participants were compensated \$20 for their time.

To ensure authenticity, credibility, and trustworthiness of the data, we followed Lincoln and Guba's (1986) recommendations. Member checking was used to ensure proper terminology, sensitivity and definitions of concepts were interpreted properly. Within one week of each interview, participants were provided by email a summary of their interview to review for misinterpretations. To maintain authenticity, participants' own words are displayed as quotations in the results. Two independent coders were used to ensure trustworthiness of the data. Researchers A and B coded the first, fifth, and ninth interviews independently. A discussion about codes lasted until consensus was made on all concepts. We also acknowledged and discussed our biases about body image and physical disability to help understand how they shape and influence the data. Triangulation of data (telephone interviews, one-on-one interviews, follow-up interviews, field notes) was used to converge information and multiple researchers worked together to apply their different perspectives to strengthen concepts (Carpenter & Suto, 2008).

## **Materials**

The LTPAQ-SCI (Martin Ginis, Hong Phang, Latimer, & Arbour-Nicitopoulos, 2012) was administered via telephone to gather information regarding participants' LTPA levels. This information was collected for purposes of the larger study and to help build rapport to increase quality of the interview data.

**Demographic information.** A fact sheet was used to gather general self-reported socio-demographic information about the participants. This data included information about age, gender, weight (if known), height (if known), ethnicity, age at the time of

injury, level/severity of injury, and their American Spinal Injury Association (AIS) classification (if known).

### **Data Coding and Analysis**

In GT methodology, data collection and analysis are done simultaneously. An initial step of analysis was transcription of the interviews (converting oral conversation into written text) done verbatim immediately after each interview. Non-verbal information (e.g., silence and emotional cues), collected in field notes during the interviews, was embedded into the transcripts. Analysis of GT involves coding and organizing data. Charmaz (2006) describes three main coding processes: initial coding, focused coding, and axial coding. Initial coding is the first coding stage involving examining differences and similarities between events, actions and interactions. This was done line-by-line where codes were grouped together later into categories and given a name. Focused coding is the next step of analysis which is more conceptually involved. The codes are more directed, selective and conceptual than in initial coding and is completed iteratively by constantly comparing data with data, an integral component of GT analysis (Corbin & Strauss, 2008). According to Charmaz (2006) it is important to keep a memo of information throughout analysis to organize conceptual understandings, analytic examinations, and to record thoughts, questions and relationships between interviews. The last stage of coding is axial coding and follows the development of a model where a core category is identified. Axial coding relates categories to subcategories, outlines the boundaries of a category and reassembles the data from initial coding to give coherence to the emerging analysis (Charmaz, 2006). The core category is represented in the preliminary model in Figure 2-1.

## **Results and Discussion**

Overall, participants explained that their SCI directly affected how they see, feel, think, and act towards their body. This demonstrates the multidimensionality of body image and supports the importance of exploring body image experiences in people with SCI as participants' injuries in this study directly impacted their body image. A broad spectrum of body image experiences were reported among participants (ranging from very negative to very positive). Generally, participants' body image fluctuated, meaning their body image experiences varied day-to-day from negative experiences to positive experiences. This supports the notion that body image may be better understood as reflecting a continuum of state experiences rather than being static (Melnik, Cash, & Janda, 2004). As well, positive body image categories in this study were not simply the opposite of negative body image characteristics similarly found in previous research (e.g., Cash, Phillips, Santos, & Hrabosky, 2004), reinforcing that positive body image is distinct from negative body image (e.g., Striegel-Moore & Cachelin, 1999). Despite body image being described as a day-to-day experience, some participants (e.g., Larry, Danny, and Caroline) did describe having an overall positive body image. Regardless of their current body image, all participants were knowledgeable about important components of positive body image for people with SCI.

The following main categories for positive body image were found: body acceptance, body appreciation and gratitude, social support, functional gains, independence, media literacy, broadly conceptualizing beauty, inner positivity influencing outer demeanor, finding others who have a positive body image, unconditional acceptance from others, religion/spirituality, listening to and taking care of

the body, managing secondary complications, minimizing pain, and respect. These categories (and their subcategories) are delineated below. Interestingly, there were many consistencies in positive body image characteristics reported by participants in this study with those reported by participants (who did not have a SCI) in previous research (e.g., Frisen & Holmqvist, 2010; Wood-Barcalow et al., 2010). For instance, all the characteristics synthesized by Tylka (2011) were found to emerge. However, some unique characteristics particularly relevant for people with SCI (e.g., resilience, improvements in function and independence, respect, managing secondary complications, and minimizing pain) also emerged. Our preliminary positive body image model links connections and relationships of all the main categories and can be found in Figure 2-1. The main core categories to positive body image are body acceptance and body appreciation and gratitude. These characteristics emerged as the most stable with regards to positive body image experiences and led to the emergence of other surrounding characteristics (e.g., resilience, function, independence, listening to and taking care of the body) in the model (Figure 2-1).

### **Body Acceptance**

Overall, body acceptance was found to be the core category to positive body image. This is depicted in the model (Figure 2-1) as the centre of all other positive body image categories as acceptance had to be present in order for any other characteristic to emerge. After acceptance is achieved, deeper layers of positive body image (e.g., body appreciation and gratitude) followed. This is particularly pertinent for someone who has a SCI as they must accept the disability and their body in order for positive psychosocial adjustment to occur (Wright, 1983). In fact, past research has shown that acceptance of a disability is imperative in positive adjustment to a SCI (Woodrich & Patterson, 1983).

In this study, body acceptance was discussed by participants as coming to terms with their body and disability, getting over aspects that cannot be changed (e.g., such as immobile limbs), loving the body regardless of not being completely satisfied with all aspects, ignoring superficial qualities, and focusing on their assets rather than shortcomings. For example, Larry suggested,

...having a positive body image means loving yourself and accepting the flaws that you have as well as the positive side so you know just accepting everything that comes with you that I think is the best way for anybody to have a positive body image is just to accept it and to be the best person you possibly can be...

Lizzy believed accepting the body was an integral component to positive body image. For example, she said, "...just a lot of it is acceptance, this is the way I am now and I accept that." She also discussed accepting her body despite the fact she is not completely satisfied with the fact she cannot stand in front of a mirror. She said, "...I mean again, it comes back to acceptance, you know like it's nothing I can change [her injury] yeah would I sooner like to see myself in a mirror standing, definitely." Mark admitted to having a negative body image, however he did believe in the importance of not focusing on parts of the body that cannot be changed, such as atrophy in his legs or the fact he cannot stand. For example, he said, "... you have to accept yourself in a new way but once you accept yourself ... then probably have a better view on your body..."

### **Body Appreciation and Gratitude**

The next main category following acceptance is body appreciation and gratitude. As depicted in the model (Figure 2-1) body appreciation and gratitude emerged as deeper layers from the core characteristic acceptance. This is illustrated as a pyramid hierarchy

because once participants accepted their body they were able to appreciate and show gratitude towards it. Body appreciation and gratitude was discussed as learning to appreciate all aspects of the body (e.g., health and function) and not focusing solely on appearance. Learning to not take their body for granted and being grateful for the aspects of their body they regained such as function and strength led to improved independence, contributing to more positive body image experiences. Overall, the following four main components of body appreciation and gratitude which contributed to positive body image were discussed: function, independence, health, and appearance.

**Function.** In this subcategory, participants explained having overall appreciation for the body function they regained since their injury. For example, Larry discussed being grateful for the function he has in his upper body despite having tetraplegia. He said, "... it can always be worse you know it can always be worse. I tell people all the time that I am so lucky to have my arms and you know I have all my strength..." Danny, emphasized the importance of focusing on body strengths not weaknesses. For example, he said,

...focus on your abilities and not your disabilities, that's one thing I have learned over the years. Don't focus so much on what you can't do, focus on what you can do with your body and accentuate with that and build on that... instead of looking at your disability, look at your ability...

**Independence.** This subcategory emerged because participants consistently discussed the importance of appreciating the level of independence they achieved. For example, Lizzy praised herself for what her body could do. She said, "... I pride myself on being independent..." and when asked what might promote a positive experience with the body, she said, "I guess if you feel some sort of gain that you've done something like

let's say transferring well, getting dressed becomes easier... that could be an accomplishment..." Danny would remind himself of the amount of independence he has gained since his injury and would appreciate this aspect of his body image.

**Health.** Some participants discussed the importance of appreciating their health and not taking their current health status for granted. For example, Samantha discussed not taking her health for granted and taking better care of her body now since her injury. She said,

... I have started to take better care of my body because I realize that it's so fragile especially now that I am so reliant on my arms to get around like I work out as much as I do and try to eat really healthy and stuff whereas before [before her injury] I was a smoker and a partier and stuff whereas now I would never do that...

Some participants appreciated having minimal secondary health complications. Being around other people who had a SCI who suffered from more complications reminded them that their situation could always be worse, therefore they should always be grateful. Caroline disclosed being grateful for being given a second chance at life and never taking that for granted. She said,

... if you have an accident and you know your legs have been taken just taken away from you it just makes you more aware of what you have to lose and so you have been given a second chance and you don't want to waste it...

**Appearance.** One participant discussed being grateful that she is not more overweight as being overweight is a common issue for people with SCI. She also talked

about being grateful she still has certain attributes such as muscle tone in her legs, for instance she said,

... I do see you know things about I do still have some muscle tissue in my legs some muscle in my legs that keep them a little more sort of bigger than you know sort of some of the really tiny boney legs of people with my level of injury and supersized knees... I try to be grateful.

### **Social Support**

Social support was found to be a key component for the development and maintenance of body acceptance, as well as facilitating other peripheral positive body image characteristics in the model (Figure 2-1). If social support was not present or perceived by a participant, then s/he struggled with forming other surrounding positive body image characteristics (e.g., listening to and taking care of the body, resilience, or functional gains). Perceived social support played a particularly important role during the adjustment period for most participants in this study. The adjustment period was described as the most negative in terms of body image experiences. Benefits of a positive social support network have been identified as critical factors in both acute and long-term adjustment to disability in numerous studies (e.g., Elliott, Herrick, & Witty, 1992; Elliott, Herrick, Witty, Godshall, & Spruell, 1992). Therefore, it is not surprising that if social support was not present, then acceptance, appreciation and gratitude of the body seemed to be more difficult to establish for those participants. For Caroline, her mother-in-law played an important role when she was still hospitalized. Caroline believed she had a positive body image and linked this to her social support network. She said,



... a huge percentage of my success rate is that my family first from the beginning like I said my mother-in-law... she drove to Hamilton every day, every day yeah and she would bring me baked goods and would lie on the floor when I was on the Stryker upside down and would feed me...

Social support was also demonstrated through being around other people who have a physical disability or SCI. For instance, when asked what the most comfortable situation is with their body, most participants said being around other people who have a physical disability. This is because being in a homogeneous group helped facilitate feelings of acceptance, appreciation, and gratitude. Will described being able to relate better with other people who have a SCI. For example, he said, "The most comfortable situation for me is when I am around other people who have a disability like SCI or otherwise so because I can relate to them and they can relate to me..." Samantha explained how being around other people who have a SCI feels as though she is part of a peer support system because everyone is dealing with the same issues. She said, "Just because everyone would be dealing with the same stuff that you'd be dealing with like having everyone would have a little belly or everyone would be in a wheelchair and... everyone is dealing with the same stuff so sort of again going back to that peer support..." Overall, perceived social support, whether from family, friends, or those who have a SCI, helped facilitate a sense of acceptance towards the body allowing other positive body image characteristics to emerge.

## **Resilience**

As illustrated in the model (Figure 2-1), the categories, resilience, functional gains, and independence, are represented as another pyramid hierarchy and emerged

through the facilitation of social support. This is supported by past research which has demonstrated social support serving as a facilitator of resilience coping in people with (White, Driver, & Warren, 2010) and without a SCI (Martin & Martin, 2002). After body acceptance, participants discussed the ability to act resilient which then led to the focus of regaining function which contributed to accomplishments in independence. Resilience refers to an individual's personal qualities that allow them to prosper in the face of adversity (Bonanno, 2004). Resilience was discussed by participants as dealing with setbacks and taking on challenges that accompany a SCI directly. Caroline explained the importance of having resilience after a SCI to body image and stated resilience follows acceptance. She said,

... you have to be realistic about stuff and if you can accept changes in your life and accept people helping you ... and keep trying to wake up with a good positive outlook and be nice and kind to yourself... if you're not going to accept then you're not going to want to bounce back because you're putting up road blocks...

Individuals need to accept their situation and their body in order to face adversity with success. Caroline mentioned how this is particularly pertinent for someone with a SCI who experiences more daily challenges than someone with an able-body. Resilience was described as greatly important for gains in function and strength. Once participants were able to face the adversity of their injury, they were able to commit to focusing on rebuilding strength of their body.

### **Functional Gains**

After reaching resilience, participants discussed being able to focus on regaining some of their body function. Many participants stated how gains in their function contributed largely to feeling positive about their body. For example, Danny said regaining function in his arms, despite the prognosis from his doctors that he would never use his arms again, was one of the most positive experiences with his body. He tried to focus on what he has functionally accomplished with his body, but also emphasized the fact that body image fluctuates day-to-day. He said,

... just focus on what you have accomplished. I know with me I have accomplished the fact that they told me I wouldn't be able to move my arms but now I can get in and out of [his wheelchair] you know by myself... I always focus on the positive aspects... but it goes day by day.

Caroline also described a similar experience. Despite being told by doctors that she would never feel or move her body again, she was able to regain movement in her toe while she was still hospitalized. She explained this moment,

I was laying in bed and was thinking really hard to get something to move and all of a sudden my toe moved... for me, that was the beginning of when the light went on and I was like 'oh man, this is a door opening for me this is going to be great.' So that was huge, that moment was huge.

Another remarkable moment with her body was when she was able to stand and walk using parallel bars. This ability led to tremendous positive emotions towards her body. Function was suggested by Star to be particularly important for someone who has a SCI because after enduring a SCI and having initially lost a lot of function, a sense of

overwhelming pride towards any regain of function facilitates positive emotions towards the body.

### **Independence**

After regaining strength and function of the body, participants discussed being able to become more independent. The categories functional gains and independence illustrate main differences in positive body image for people who have a SCI as opposed to people who do not have a SCI. Function and independence are aspects of body image that may be taken for granted by people who do not have a physical disability, and therefore do not represent positive body image experiences as saliently as for someone with a SCI. A sense of independence was discussed as pivotal to positive body image. For example, Samantha explained how small aspects of independence such as being able to shower on her own were hugely important to her body image. She said,

... when I started to feel really positive about myself is when I started to feel independent again... So that was huge to me at 18 to be able to finally shower on my own again and do all my basic care... I think is huge thing in terms of how you feel about your body and you know your body is finally not failing you anymore you are finally able to use it for something positive.

Caroline discussed how an accomplishment such as getting her license to drive again was important to her positive body image. This also allowed her to get a job and work again after her injury. She said,

... my independence was taken away so I wanted it to come back somewhat so I got my licence in driving... I got a job which made me feel independent and plus the fact that even though it took a lot of energy to lift into my car, my chair

in and out of the car, to get myself up really to be at work on time, and that I could do this and keep up with everybody else at work so to me this was a great accomplishment.

### **Media Literacy**

The categories media literacy, broadly conceptualizing beauty, and inner positivity influencing outer demeanor all have a bidirectional relationship with the core categories (body acceptance, appreciation and gratitude) as depicted in the model (Figure 2-1). Participants who accepted and appreciated their bodies tended to not buy into media portrayals of beauty and had a broader concept of beauty. Furthermore, participants who shared those beliefs about beauty found it easier to accept their own bodies.

Participants who had a positive body image described not being affected by the media. Some participants also explained that the media was irrelevant to them since they do not have an able-body and therefore were unaffected by this type of societal pressure. Most participants understood the fabricated nature of the media and did not buy into media messages of 'ideal' bodies. For example, being asked if the media impacts his body image, Larry said, "No. No, not at all I've never bought into it I think it's you know I think it's ridiculous personally... They fix everything and it's [alteration of images] have been happening for years..." Lizzy also explained not buying into the media. She said, "I think I'm old enough to distinguish what is being fed to us as a I don't want to say propaganda but pretty much."

### **Broadly Conceptualizing Beauty**

Broadly conceptualizing beauty is theoretically connected to media literacy. This is because most of the participants who understood the fabricated nature of the media had

a broader concept of beauty and more positive body image. They believed all human bodies are beautiful (e.g., varying shapes and sizes). For example, Larry had the broadest concept of beauty. He said, "... everybody has a body and everybody has we all have different shapes and we all have different sizes and we are all the same..." and he also said,

... to be the best it can be that's the perfect body whether you are 6'6 or whether you are 5'2 you know or whether you are really lean natural body type or whether you are thick and blocky type of body just push that body and work it so that it is itself the best that it possibly can be and that's the perfect body.

Having a broad concept of beauty was also linked to the next category, inner positivity influencing outer demeanor; those who had a broad definition of beauty also believed aspects other than appearance were beautiful, such as personality.

### **Inner Positivity Influencing Outer Demeanor**

Participants who were media literate and had a broader sense of beauty believed some beauty comes from within the body. For example, a person's inner personality or attitude translated into feeling positive on the outside. For example, Will said, "I think how you feel in the inside reflects on how you feel on the outside... how you feel on the inside reflects on how you feel on the outside or how you look..." Danny believed a positive attitude was key to having a positive body image. For example, he said,

Positive attitude I think is key. If you have a positive attitude then you look at things in a better way and if you are pessimistic then you are going to look at everything like bad. You can be in the best shape and still be like 'man, this

sucks!' I think a good positive attitude would be key foundation to positive body image.

Overall, having a broad outlook of beauty included believing beauty encompasses many different appearances and inner qualities such as personality and attitude. Participants who shared this outlook also did not buy into fabricated ideas of beauty perpetuated by the media because they believed in a more inclusive definition of beauty.

### **Finding Others who have a Positive Body Image**

This category is linked to unconditional acceptance from others because those who chose friends who had positive body image experiences also perceived being accepted by them unconditionally. These categories also have a bidirectional relationship with the core categories: body acceptance, appreciation and gratitude. Perceiving unconditional acceptance from others and surrounding oneself with others who have a positive body image may facilitate acceptance of one's own body and vice versa. Those participants who learned to accept their body also consciously looked for other people who had a positive body image. They would not bother spending time with people who were negative or overly critical about appearance. For example, Samantha said,

I think surrounding yourself with positive people is really important like people who also feel good about their body who aren't always putting their body down and stuff that is going to weigh you down... and just surrounding yourself with positive people and positive activities...

Caroline disclosed that she consciously made an effort to choose friends who made her feel positive about her body and accepted her body.

### **Unconditional Acceptance from Others**

For this category, participants explained perceiving unconditional acceptance from important people in their lives such as friends and family. Star discussed being unconditionally accepted by her husband despite the fact her body includes many more daily challenges such as autonomic dysreflexia<sup>1</sup>. For example, she said, "... the people that have come into my life and say my husband in particular who loves me to no end it just blows my mind..." She described how this unconditional acceptance assisted in her own acceptance of her body. Mark discussed how most of his friends and his girlfriend in particular played an important role in feeling positive and accepting his body regardless of his being in a wheelchair. This unconditional acceptance from others made him feel more comfortable with his body.

### **Religion/Spirituality**

This category with relation to positive body image was discussed by only a couple of participants. For Will, it played a very salient role in his positive body image experiences. He discussed how reading inspirational books and finding faith helped him come to terms and enjoy his body since his injury. For example, he said, "Well I'm unique in a way that like I said I have I think my faith has brought me this far..." This relationship is illustrated as unidirectional in the model (Figure 2-1) with the core categories as religion/spirituality may lead to body acceptance, however acceptance would not necessarily lead to becoming religious or spiritual.

### **Listening to and Taking Care of the Body**

Overall, being in-tune with the body by being aware of metabolism, bladder, and bowel changes since a SCI was found to contribute to more positive body image experiences. This was also expressed as a positive behaviour of the body, such as

<sup>1</sup>Autonomic dysreflexia is an acute syndrome of excessive sympathetic output (e.g., sudden rise in blood pressure) which can be life threatening (Blackmer, 2003).



exercising and participating in leisure activities. This relationship with the core categories is illustrated as bidirectional in the model (Figure 2-1), as taking care of the body also contributed to accepting the body. Participants who had learned to accept and appreciate their bodies also learned to listen to and take care of their bodies. They would eat a healthy balanced diet and be well attuned to changes in metabolism since their SCI. For example, Star said, "... I try to eat healthy so I guess that is a behaviour toward my body and I do try to take care of my body and I talked about that already with the stretching and the loving moments with my legs...". Although Lizzy lived a sedentary lifestyle, she also believed in the importance of engaging in regular physical activity. She struggled to refrain from overeating, but she believed eating a healthy diet was important for someone who had a SCI to feel more positive about their body. Managing proper exercise and eating routines promoted healthy weight management which directly affected daily routines such as transferring and general transportation in a wheelchair. Larry discussed engaging in exercise for the intrinsic benefits, such as improvements and maintenance of his functionality, mood improvement, and feeling more alert. He described being in the Rick Hansen Relay as one of the most positive experiences with his body,

... I felt I mean I feel fairly positive and fairly comfortable on a daily basis, just regularly but after Rick Hansen Relay and spending 34 days on the road with them and really physically pushing myself every day I felt really good I felt physically, more energy, felt more alert, just general all around I felt better...

Samantha explained the importance of taking care of the body by being active and eating well. She said,

... it all boils down to taking care of yourself like if you sit around and don't take care of yourself and don't work-out and get overweight and get sick of course you are not going to see yourself in a positive way, you know, put a little effort in it like you know work-out and keep active and eat well...

This category was found to emerge differently than in previous positive body image research. For example, Wood-Barcalow and colleagues (2010) found taking care of the body via healthy behaviours was a result of positive body image. However, in this study, listening to and taking care of the body was discussed to both promote and maintain positive body image experiences. This difference may accentuate the uniqueness of SCI as taking care of the body has even more fundamental importance due to changes resulting in susceptibility to more health complications (e.g., urinary tract infections, coronary heart disease).

### **Managing Secondary Complications**

Listening to and taking care of the body is illustrated as a unidirectional relationship with managing secondary complications in the model (Figure 2-1). Participants who were attuned with their body also managed secondary complications with greater success and this was important to positive body image. Samantha explained that listening to her body involved being in-tune with any secondary complications that may be arising, such as a urinary tract infection. By staying on top of secondary health issues and not letting any complications exacerbate by ignoring them, she would have more positive body image days. During her follow-up interview, Caroline was asked to elaborate on how managing secondary complications and bowel routines/complications would influence her body image. She discussed the importance of eating a healthy diet

and exercising as it can make a difference with respect to bowel routines which contributes to body image. She said,

... I have to really watch what I eat I have to eat like bran and yogurt and stuff like that in order to function properly and so the exercise is good for bowel movements I just can't have it all in the same day haha I have to be on top I feel you have to be on top of it.

Caroline discussed the delicate balance between managing eating, bladder/bowel, and exercise routines and how it is complexly related to positive body image for someone who has a SCI. This is another example of a unique relationship of positive body image for people with SCI.

### **Minimizing Pain**

Listening to and taking care of the body is also illustrated as a unidirectional relationship with minimizing pain in the model (Figure 2-1). There are four main types of pain found to follow a SCI: musculoskeletal, visceral, at-level neuropathic, and below-level neuropathic. Musculoskeletal pain has been documented as the most prevalent pain experienced by people with SCI and has been described as dull and aching arising from musculoskeletal structures (Siddall, McClelland, Rutkowski, & Cousins, 2003). This type of pain has been suggested to be the most manageable and can be treated by correcting abnormal posture or through exercise and environment modifications. Therefore, listening to and taking care of the body (e.g., exercise) can be understood as helping minimize musculoskeletal pain. On the contrary, there is much less that can be done as treatment for neuropathic pain<sup>1</sup> (Siddall & Middleton, 2006). The participants in this study described experiencing either musculoskeletal or neuropathic pain. Star suffered

<sup>1</sup>Neuropathic pain derives from damage to the central or peripheral nervous system and is described as burning, aching, or shooting sensations (Siddal & Middleton, 2006).

from musculoskeletal pain and believed pain is detrimental to positive body image – a unique aspect of SCI. She said,

... even pain I never really talked about that but that can be a pretty big determinant of sort of positive body image you are always in pain and you don't and you don't really feel like doing anything I think umm you know to find ways to minimize that sort of feature...

Samantha mentioned experiencing less chronic back pain would make someone feel physically better about their body. Lizzy suffered from neuropathic pain and although treatment is limited for this type of pain, she mentioned that if her pain could be minimized, she would feel physically more positive about her body. Participants explained pain to be a daily experience, therefore, it is not surprising that minimizing pain (musculoskeletal in particular) would contribute to positive body image.

### **Respect**

One last category that was mentioned to contribute to positive experiences with the body was having a sense of respect. This category has a bidirectional relationship with the core categories of body acceptance, appreciation and gratitude. Perceiving respect by others may contribute to acceptance of the body. As well, accepting and appreciating the body may provide greater self-respect and dignity. When asked what matters the most to body image for someone with a SCI, Caroline said,

...just because I am in a wheelchair I am respected for just being a human being intellectually and that people respect me for who I am and not look at me and be like 'oh look at that poor girl in a wheelchair'...

She discussed how being treated with respect while grocery shopping is important to her body image and wants to be treated as anybody else would in society. For example, being consistently asked if she needs help at a grocery store threatened her sense of dignity and autonomy. Lizzy discussed a time she felt she was being treated as if she were invisible to other people at a pharmacy. She described people budding in front of her in line and the pharmacist not noticing her or providing her service. Lizzy also discussed the need to be treated by other people with respect. She said,

I developed a thicker skin just because I'm in a wheelchair doesn't mean I should be treated any different than anyone else. Sometimes when people see me talk, they look, because it's like they think I'm not supposed to have a thought process or good communication skills because I'm in a wheelchair.

Contextual factors, such as accessibility, also contributed to a sense of respect. For example, some participants discussed the importance of exercise facilities being accessible. Overall, experiences of respect resulted in positive body image experiences for participants in this study.

### **Similarities and Differences in Positive Body Image Findings**

One of the most interesting findings is the consistency of positive body image characteristics reported by participants in this study with those reported by participants without a SCI in previous research (e.g., Frisen & Holmqvist, 2010; Wood-Barcalow et al., 2010). In fact, every positive body image characteristic synthesized by Tylka (2011) was mentioned by participants in this study. This reinforces the notion that positive body image may be more universally constructed demonstrating more consistencies across groups than differences, in support of a substantive theory of positive body image.

Consistencies may be due to the fact that positive body image reflects more stable characteristics (e.g., acceptance) that do not rely on changeable features (e.g., appearance).

This study also demonstrates there are some unique characteristics to positive body image for people with SCI (e.g., functional gains, independence, managing secondary complications and minimizing pain). These unique characteristics may be understood as deriving from distinct physical changes to the body that occur as a result of a SCI. For example, the loss and then regain of body function is a uniquely salient experience of having a SCI that someone with an able-body would not necessarily consider when thinking about body image. Furthermore, closely linked to the loss and regain of function is the loss and regain of independence, another unique feature that someone without a SCI may take for granted. Lastly, secondary complications and pain were discussed by participants as direct results of having a SCI. These experiences were explained to occur daily, another feature some individuals may not experience or relate to their body image.

### **Conclusion and Implications**

The purpose of this study was to explore positive body image experiences among people who have SCI. There may be a misleading notion that people who have a SCI must have a negative body image. Contrary to research findings of negative body image experiences in people with SCI (e.g., Taleporos & McCabe, 2002), findings from this study reveal positive body image experiences can exist following a SCI. This supports the idea that anyone (e.g., someone with a physical disability) can have a positive body

image as positive body image does not symbolize having a 'perfect' body in line with the cultural ideal (Tylka, 2011).

Currently, there is a push for rehabilitation research to focus on addressing the impact of positive personal qualities rather than solely the impact of negative characteristics (Dunn & Dougherty, 2005). Therefore, addressing positive body image may be one important avenue in rehabilitation research. In fact, there is insufficient empirical research that focuses on positive psychology particularly for people with SCI (Wilson et al., 2013). The rehabilitation setting is an important area to target body image interventions because participants explained the adjustment period after their injury to be the most negative in body image experiences. Rehabilitation experiences may also set the context for subsequent body image experiences. Participants suggested that social support and being surrounded by others who also have a SCI helped them come to terms with their body (i.e., accept their body). Therefore, mentorship programs designed to have someone with a SCI who is well adjusted and has positive body image meet with someone who is newly injured on a weekly basis may help facilitate acceptance and appreciation. Acceptance and appreciation emerged as the centerfold of positive body image and therefore should be the main objectives of body image interventions. Once acceptance is fostered, other positive body image characteristics can be strived for, such as body appreciation and gratitude. Mentors can exemplify the many abilities they have, such as function in their arms which lead to accomplishments in independence, all of which contribute to positive body image.

### **Limitations and Future Directions**

This study was designed as a pilot and therefore a modified GT methodology was utilized forming a preliminary theory. Findings are preliminary in nature as the design was intended for exploratory purposes. Therefore, conclusions and the use of the current model may be limited and not applicable to everyone who has a SCI. For example, participants in this study had an overall high level of function, independence, and physical activity. Therefore, due to some of these characteristics participants may have had more positive body image experiences than is typical for this population.

Future research should continue to investigate positive body image in people with SCI to develop a substantive theory of positive body image as there is evidence that similar positive body image experiences (e.g., body acceptance and appreciation) occur across populations, such as in people with SCI. In addition, future research should investigate if current positive body image measures (e.g., BAS; Avalos et al., 2005 and the Body Esteem Scale; Franzio & Herzog, 1986) are psychometrically valid and reliable in people who have a physical disability as these measures have been generally validated in predominately White able-bodied women. Validation of such measures is imperative for future research in the investigation of the implications of positive body image on well-being and quality-of-life across samples.



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Table 2-1

*Participant Characteristics*

Participant	Age	Gender	Age at Injury	Level of Injury	Severity	AIS Classification	Years Post-Injury	Height (feet)	Weight (lbs)	LTPA
1. Rebecca	26	Female	21	T6	Complete	A	5 years	5'7"	110	2/180 mins
2. Samantha	32	Female	18	T1	Complete	A	14 years	5'9"	140	3/60 mins
3. Will	42	Male	38	C6/C7	Incomplete	B	4 years	5'11"	260	3/120 mins
4. Lizzy	44	Female	34	T7	Complete	A	10 years	5'4"	unknown	0
5. Mark	21	Male	17	C7	Incomplete	B	4 years	5'8"	190	3/30 mins
6. Larry	48	Male	39	C3	Incomplete	D	9 years	5'11"	180	1/120 mins
7. Caroline	63	Female	27	C3/C4/C5	Incomplete	D	36 years	6'2"	214	2/60 mins
8. Star	36	Female	18	T3	Complete	A	18 years	5'4"	121	2/60 mins
9. Danny	35	Male	19	C5	Incomplete	C	16 years	5'9"	215	0

*Note.* LTPA scores based on self-reported number of days in the last 7 days participants took part in moderate to vigorous intensity leisure activity and amount of consecutive minutes they engaged in that activity. Recommendations are at least 20 minutes of moderate to vigorous activity for 2 times a week of aerobic and strength training activities.

Table 2-2

*Interview Questions*

- 
7. Can you tell me a bit about how you view your body?
  8. Tell me about how you first adjusted to your body after your injury?
  9. Will you talk about how you see and think about your body now?
    - c. How about before your injury?
    - d. How about acutely after your injury?
  10. Overall, how do you feel about your body now?
    - c. How about before your injury?
    - d. How about acutely after your injury?
  11. In what ways do you act towards your body?
    - c. How about before your injury?
    - d. How about acutely after your injury?
  12. How does the media impact how you feel about your body currently?
  13. What do you think having a positive body image means?
  14. In what specific situations might someone with a SCI feel comfortable with their body?
  15. Tell me about something that may promote a positive experience with the body shortly or immediately after a SCI.
  16. What are some ways someone with a SCI may see him or herself in a positive way?
  17. What are some examples of good thoughts a person with a SCI may have about their body?
  18. How do you think people with a SCI in general go about feeling positive about their body?
  19. What are some ways a person with a SCI may act in a positive way towards their body?
  20. How might someone with a SCI build a positive body image?
  21. Overall, what is your understanding of a positive view on the body?
  22. Is there anything else that you feel is important when it comes to feeling healthy and positive about the body, especially for someone with a SCI?
-



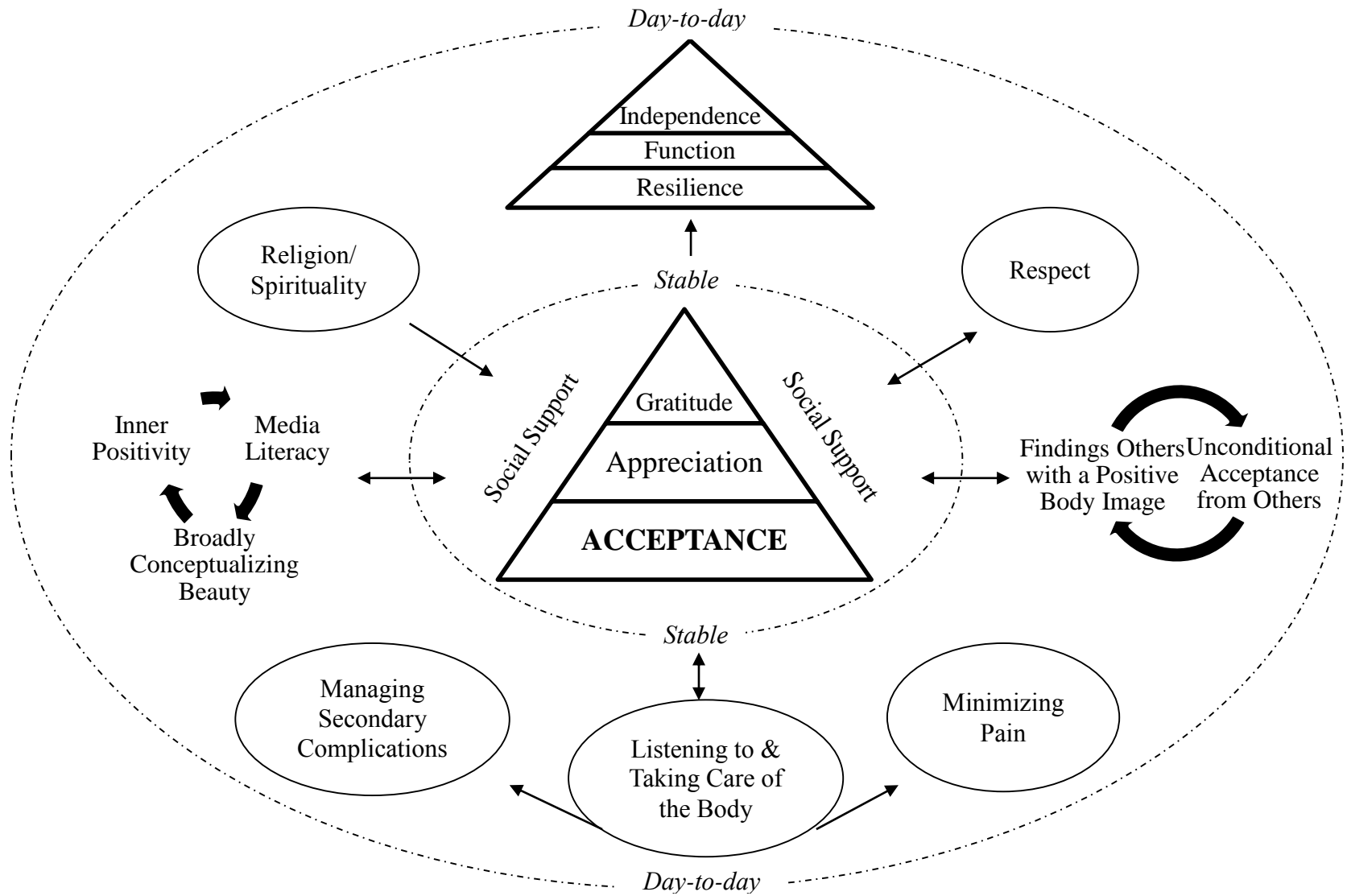


Figure 2-1. Preliminary positive body image model for people with SCI

## **General Discussion and Conclusion**

Everyone has body image experiences that may be positive or negative in nature (Cash & Smolak, 2011). Although everyone has body image experiences, research has focused primarily on able-bodied experiences, overlooking body image in individuals who have a physical disability. As well, research in body image has focused on preventing and treating the negative features creating a one-sided understanding of body image experiences (Cash & Pruzinsky, 2002). Therefore, this thesis was designed to address two main limitations in the literature (1) the lack of understanding of body image experiences outside the predominately able-bodied population; and (2) the limited positive body image research. Therefore, the purpose of this thesis was to explore body image in people who have a SCI through two studies. The first study broadly explored body image experiences (and inductively discovered self-presentation as an important and related concept) and the second explored positive body image experiences.

Interestingly, every participant described their injury as affecting all dimensions (perceptual, cognitive, affective, and behavioural) of their body image. Furthermore, participants described both negative and positive body image experiences demonstrating that people with SCI can have varied experiences with their body. Most interestingly, it appears that positive body image can exist following a SCI, refuting the fallacy that people with SCI may have only negative body image. Furthermore, as depicted in each model (Figures 1-1 & 2-1), it is evident that positive body image characteristics are not the opposite of negative body image characteristics. Rather, positive body image experiences were fostered by body acceptance, appreciation and gratitude, whereas negative body image experiences were represented by negative perceptions, thoughts, and

feelings about appearance. Fostering body acceptance did not mean participants were completely satisfied with all aspects of their bodies such as appearance. Rather, they exuded contentment with their entire body and did not rely on superficial qualities for enjoyment. This supports the notion that positive body image should be understood as distinct from negative body image (Striegel-Moore & Cachelin, 1999). These findings also encourage future research to explore the uniqueness of positive body image, especially in samples other than young able-bodied individuals.

### **Contributions to the Body Image Literature**

This thesis provides contributions to the body image literature. First, it contributes to the understanding of negative body image experiences in people with SCI. Second, it contributes to the positive body image literature. Third, it supports the fluctuating nature of body image (i.e., state experiences; Melnyk, Cash, & Janda, 2004), as experiences were explained to vary day-to-day among participants. Lastly, it demonstrates the complex relationship between body image experiences and self-presentation.

With regards to the negative body image findings, it is important to note the vast importance some participants placed on appearance. There may be an assumption that after a SCI an individual may automatically place less importance on appearance and place higher value on other aspects such as health and function. Although health, function, and independence were indeed mentioned as important aspects of body image, many participants still had a profound focus on their appearance. This was particularly evident in the women who seemed preoccupied over receiving attention from the opposite sex about their physical attractiveness. Able-bodied women have been found to report higher levels of appearance investment than men (Cash, Melnyk, & Hrabosky,

2004). Therefore, it is interesting to note the striking similarity between participants in this study and findings in other samples.

Positive body image experiences were found to be centred on body acceptance, appreciation and gratitude. This is a close replication of the findings synthesized by Tylka (2011) thereby supporting a substantive theory demonstrating some universality of positive body image. Conversely, distinct positive body image characteristics particularly relevant for people with SCI (e.g., functional gains, independence, managing secondary complications, minimizing pain) were also found. This demonstrates the importance to more broadly explore body image experiences outside the able-bodied population as able-bodied experiences are not entirely representative for everyone. One concern of generalizing positive body image experiences from able-bodied experiences is that measures such as the Body Appreciation Scale (Avalos, Tylka, & Wood-Barcalow, 2005) or Body Esteem Scale (Franzoi & Herzog, 1986) may be invalid for people with a physical disability. This greatly limits future research in the area resulting in a lack of understanding of the implications of positive body image in diverse samples.

The third contribution this study provides to the body image literature is support for the contention that body image is a fluctuating phenomenon (i.e., state experiences as opposed to merely trait characteristics; Melnyk et al., 2004). Participants consistently described their body image to changing day-to-day rather than being static. For example, depending on their success with daily tasks (e.g., bladder/bowel routines) they may have more positive or negative body image experiences. This is consistent with recent developments in the body image literature among able-bodied samples exploring the fluctuating nature of body image (e.g., Melnyk et al., 2004).

Another important finding is that body image was closely linked to self-presentational concerns and tactics. Although self-presentation is a distinct construct as it involves the beliefs about perceptions that others have, there is also conceptual overlap between the two constructs. For example, one's body image can influence self-presentation and conversely self-presentation can influence body image. For example, participants in this study who described more negative body image also described more distinct self-presentational concerns (e.g., concerns of incontinence and the need to be perceived as 'normal').

The above contributions to the body image literature provide direct links for future implications. For example, interventions may need to be designed in hopes to reduce the importance people following a SCI may place on appearance. There may need to be more emphasis on positive body image characteristics such as learning to accept the body rather than focusing on unreliable aspects such as the reliance of attention from others about appearance. Acceptance can be fostered through mentorship by others who have a positive body image particularly acutely following injury. Disconnection and objectification of the body seemingly stemmed from experiences immediately following injury. Therefore, efforts to educate medical professionals about positive care to individuals recently injured are imperative. Since body image was described as state-like as opposed to static, efforts to improve body image experiences are likely to be successful as body image may be malleable.

### **Contributions to the Spinal Cord Injury Literature**

There is an inadequate amount of research in the SCI literature that has explored body image. In fact, the handful of studies that briefly examined body image in people

with SCI (e.g., Bassett & Martin Ginis, 2009; Bassett, Martin Ginis, & Buchholz, 2009) employed a quantitative approach thereby missing the detail and complexity of embodiment. This thesis used a qualitative methodology allowing rich descriptions of body image experiences to emerge.

Participants disclosed their body image to be one of the very first concerns after sustaining a SCI. A SCI resulted in a changed body (appearance and function) which was directly impacted by their injury. Physical changes to appearance, strength, and function led to many psychological and emotional changes, particularly during the adjustment period. In fact, some participants disclosed that the hospitalization and rehabilitation time period was the most negative of their body image experiences. For example, some participants felt their body was scrutinized medically and treated as though it was an object that needed to be cured.

Lastly, very little research has explored self-presentation in people with SCI. Other than one study (Arbour, Latimer, Martin Ginis, & Jung, 2007) which investigated how exercise information could affect the impressions formed by able-bodied participants on targets with SCI, no research has taken an in-depth look at self-presentation in people with SCI. Interestingly, self-presentation was a completely unanticipated finding which emerged from participants themselves, since no original interview questions were formed to probe about self-presentation. Intuitively, it is not surprising that people with SCI would have inherent self-presentational concerns and tactics to help manage stigma. Participants in this study reported distinct self-presentational tactics used to help manage stigma associated with having a disability and using a wheelchair. In fact, participants explained stigma to threaten their body image. For example, some participants explained

receiving inappropriate and degrading comments about their appearance or their use of a wheelchair which negatively influenced their own perceptions and attitudes about their body by reinforcing feelings of not being accepted by society.

Understanding self-presentation in people with SCI may have direct implications for health-enhancing behaviours as self-presentational concerns can both encourage and discourage health-related activities such as exercise (Leary, 1992). Therefore, exercise facilities may need to be designed to help lessen self-presentational concerns. One approach may be to ensure full accessibility for anyone who has a physical disability. Participants in this study explained a need to be perceived as 'normal' (i.e., blending in among those who have an able-body). Having accessible exercise facilities would: (1) allow individuals who have a physical disability to enter and use equipment in the building with a sense of dignity; and (2) provide opportunities for exercise (a health-enhancing activity). People with SCI have increased susceptibility to secondary complications such as coronary heart disease (Nooijen et al., 2012) so it is crucial to try to lessen self-presentational concerns in exercise facilities for people with SCI.

Some of the findings in this study are alarming and raise attention that is needed in the rehabilitation setting (e.g., perpetuating feelings of body disconnection and objectification from medical staff, particularly immediately post-injury). Knowledge mobilization efforts should be targeted to teach medical professionals the importance of body image after a SCI. Seminars at professional conferences attended by medical staff should be led by body image researchers to voice some of the experiences newly injured patients have with their body. In particular, medical professionals need to be made aware of the importance of promoting body acceptance and appreciation - foundations of

positive body image. If experiences acutely following injury can be made more positive, this may set the context for future body image experiences for people living with a SCI.

### **Critical Disability Theory**

The conceptual lens for the current study was underpinned by Critical Disability Theory (Pothier & Devlin, 2006). This theory outlines disability as a social construct and not a consequence of impairment. It deconstructs the ingrained privileges of having an able-body since societal structures and assumptions are based on able-bodied norms. Regrettably, the dominant paradigm for understanding disability has been through the medical model which identifies the disadvantages experienced from having a disability as defined by person's medical condition. For example, a person with a SCI may be referred to as a 'patient' for the rest of their life although they may never enter a hospital for several years after recovering from an injury.

When negative inferences are made about someone with a SCI (e.g., incompetence, ill-health, asexuality), this creates a stigma resulting in social undesirability. Therefore, experiences of embodiment may, in part, be influenced by experiences of social exclusion induced by stigma. Since disability is a social construct in which inequality is purposefully designed and maintained by the status quo, the experience of a disability is therefore heavily influenced by political norms. When disability is interpreted as a social construct, it is examined under the socio-economic, cultural, and political disadvantages resulting from social exclusion (Baffoe, 2013). Body image is also socially constructed (Grogan, 2007) and therefore the interaction of experiences of disability and body image may be complex. For example, in order to reduce much of the stigma experienced by participants in this study, they would engage



in self-presentational tactics. Some participants purposely avoided exercise facilities either because of inaccessibility or fear of incontinence during activity. Inaccessibility in particular is a prime example of the disadvantages experienced by people with SCI. Exercise has been well documented to have positive influences on body image (e.g., Campbell & Hausenblas, 2009), therefore those who have a physical disability may not have the same opportunities to reap benefits not only in physical health but with body image as well. It was important for most participants to be viewed as independent, thus, they would engage in regular exercise to maintain strength and function in order to maintain or improve their level of independence. Again, if exercise facilities are not available or accessible then this creates dissonance between what is needed for someone who has a physical disability and what is made available by society.

The many social constructions behind the ingrained meanings of disability and body image were experienced intersectionally by participants. For example, there are layers of labelling within disability, specifically within SCI. After sustaining a SCI, a person is labelled almost immediately with having either paraplegia or tetraplegia. Attached to each label are ingrained assumptions about the ability of the associated person. The participants who had tetraplegia described the many frustrations that accompany such a label. They described interactions with medical staff to be sometimes degrading because they faced many negative assumptions about their ability, limiting their opportunities in many situations such as in rehabilitation. For instance, they would automatically be sized for an electrical wheelchair rather than a manual wheelchair. An electrical wheelchair is not ideal as it creates more issues with accessibility and fewer opportunities to advance in independence level. Interestingly, every participant with

tetraplegia in this study had the full capability of using a manual wheelchair.

Consequently, some participants preferred having the label 'paraplegia' in order to reduce negative inferences that accompany the label 'tetraplegia'.

Another example of intersectional experiences was among the women. It was important for the women in this study to be perceived by others as physically attractive. This drive was motivated by the fear of never attaining a partner after their injury. Therefore, the women not only experienced disadvantages from having a physical disability, but were also oppressed by being a woman. Society places much of a woman's worth in her appearance (Hesse-Biber, 2007). For example, women encounter more prejudice for being overweight and are therefore more likely to diet and have plastic surgery (Orbach, 2005). This trend has been particularly found in able-bodied women (Grogan, 2007), however, the desire to be physically attractive may be even more salient for a woman with a SCI as they must also overcompensate for the stigma associated with their disability. Therefore, the women would engage in many tactics such as dieting (for weight loss), exercise, and even the extreme of cosmetic surgery. Although men too experience societal pressures to attain a certain appearance (i.e., the male 'ideal'), it is to a lesser extent, as their worth is placed in other characteristics such as intelligence and career attainment. Therefore, perhaps the male participants in this study experienced more positive body image since their worth was not as heavily dependent on physical appearance. This was apparent as the men seemingly discussed more positive body image experiences than the women.

## **Self-Reflexivity**

A distinguished practice of qualitative research is self-reflexivity, understood as honesty and authenticity of the self, one's research, and one's audience (Tracy, 2010). As a White, able-bodied, female, novice researcher who is an average weight, height, and body mass index, I have assumptions, biases, and characteristics that influence my research. As a White, able-bodied researcher, I have ingrained privileges that should be made transparent when researching a complex construct such as disability. Since all my participants were also White, my Whiteness may not have influenced my research, as my participants and I likely shared many of the same privileges associated with Whiteness. On the contrary, my having an able-body may have limited participant's comfort for unveiling some experiences of disability. One example may be that I do not face incontinence or inaccessibility issues and therefore discussing such topics may have been too personal or a nuisance for some participants due to our lack in commonality. Fortunately, I had the opportunity to build strong rapport with some participants who then displayed more willingness to discuss personal issues such as incontinence. Rapport was built through a combination of having an initial telephone interview before meeting in-person and having trust already established by recruiting through researcher D and using snowballing procedures.

My gender may also have influenced my research process. Being a female researcher may have benefited my interactions when discussing body image with the women in my study due to shared experiences (e.g., female body objectification). However, my gender may have hindered the men's willingness to disclose experiences with their body. Research has shown it is generally more difficult for men to disclose

their concerns (Davies et al., 2000) due to socialization. However, able-bodied men have been found to be equally or even more likely to disclose body image concerns to a female researcher as opposed to a male researcher (Yager, Diedrichs, & Drummond, 2013). Therefore, my gender may not have impeded on the men's willingness to disclose their body image concerns.

Since the start of my thesis research I have developed my knowledge in body image, SCI, and qualitative research. I entered all three domains as a novice researcher and therefore had to quickly become familiar with the literature in each area in order to proceed with a coherent research objective. In particular, I had limited knowledge about disability. Thus, I entered my project with inherent assumptions and biases that inevitably influenced my research process. For example, I had a narrow view about the abilities of someone with tetraplegia. I assumed they would have nearly no movement or function in most of their upper body, specifically their arms and hands. I also assumed anyone who has tetraplegia would use an electrical wheelchair as opposed to a manual wheelchair. After interviewing my first participant who had tetraplegia, Will, I soon realized my assumptions were inaccurate. Will used a manual wheelchair since he had much of the function in his arms regained with even fine motor ability to write. This made me realize that SCI is a complex disability whereby function and sensation depends on more factors than merely the level of injury (such as AIS classification). Therefore, my assumptions about SCI were reframed through each new interaction with participants.

Finally, my own physical appearance may have influenced exchanges of responses with participants. In fact, a couple of the female participants explicitly commented on my appearance. For example, one participant during the interview

complimented me on my physical fitness. She referred to fitness as an important component of the 'ideal' body for women. Therefore, my body shape may have been used as a comparison target for this participant thereby influencing her responses about body image. In fact, her comment influenced my own body image at the time of the interview. The interview took place during the summer and the participant requested having a portion of the interview in her backyard. Since it was exceptionally warm outside, I layered down to a tank-top during the interview. Her comment about my fitness made me hyper-aware of my own appearance (e.g., clothing and fitness) thereby distracting me during the interview. Overall, my participants' views, opinions, and comments about my appearance may have influenced how they and I viewed, thought, or felt about our own bodies thereby influencing the research process. For example, my appearance may have been a reminder to participants that they do not have an able-body and therefore are further away from the 'ideal'. Furthermore, in that moment when the participant commented on my appearance I became more aware and grateful for my own body (e.g., having an able-body). Body image is a subjective experience heavily affected by social factors (e.g., interpersonal relationships, society, the media, and cultural socialization) and is therefore open to change from social interactions (Grogan, 2007). How I dressed and therefore appeared to participants during the interviews may have set the context of their responses. To reduce any influence, I generally wore semi-professional clothing (e.g., jeans and a dress shirt). However, regardless of how I dressed, my own physical appearance may have had an influence on the interview process thereby influencing some of the responses.

It is of interest to note participants' overall high level of ability. Overall, I had a highly functional sample thus providing some explanation for my research findings. For instance, many positive body image experiences were reported by participants which may be directly related to their high level of strength, function, and independence. If I had interviewed someone who uses an electrical wheelchair I may have gathered more breadth in body image experiences and possibly a different perspective on positive body image. For example, functional gains and independence may have emerged as an even more salient characteristic in the model if I had interviewed someone who uses an electrical wheelchair.

### **Conclusion**

This constructionist grounded theory study contributes to both the body image and SCI literature. Particularly, the unexpected finding of self-presentation provides an important avenue for future in SCI research and lends support for employing grounded theory methodologies. As well, findings from this study reveal positive body image experiences can exist following a SCI despite the fact participants described their injury directly impacted every dimension of their body image. Although some distinct positive body image characteristics emerged from participants in this study, there was much overlap with findings in able-bodied samples demonstrating some universality of positive body image (e.g., body acceptance and appreciation).

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## Appendix A: Research Ethics Certificate



**Brock University**  
Research Ethics Office  
Tel: 905-688-5550 ext. 3035  
Email: reb@brocku.ca

Bioscience Research Ethics Board

### Certificate of Ethics Clearance for Human Participant Research

DATE: 5/28/2013  
PRINCIPAL INVESTIGATOR: GAMMAGE, Kimberley - Kinesiology  
FILE: 12-253 - GAMMAGE  
TYPE: Masters Thesis/Project STUDENT: Aly Bailey  
SUPERVISOR: Kimberley Gammage

TITLE: Exploring Body Image Experiences among Individuals who have a Spinal Cord Injury

#### ETHICS CLEARANCE GRANTED

Type of Clearance: NEW

Expiry Date: 5/30/2014

The Brock University Bioscience Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 5/28/2013 to 5/30/2014.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 5/30/2014. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- New information that may adversely affect the safety of the participants or the conduct of the study;
- Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

\_\_\_\_\_  
Brian Roy, Chair  
Bioscience Research Ethics Board

**Note:** Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

## **Appendix B: Letter of Invitation**

**Project Title:** Exploring Body Image Experiences among Individuals who have a Spinal Cord Injury

**Principal Investigator:** Dr. Kimberley L. Gammage, Associate Professor, Department of Kinesiology, Brock University

**Student-Investigator:** Aly Bailey, Master's Student, Faculty of Applied Health Sciences, Brock University

I, Kimberley Gammage, Associate Professor from the Department of Kinesiology, Brock University, invite you to participate in a research project entitled "Exploring Body Image Experiences among Individuals who have a Spinal Cord Injury".

The purpose of this study is to better understand body image for individuals who have a spinal cord injury.

Only participants who indicate no previous history or diagnosis of a clinical eating disorder, who are 18 years of age or older and at least 12 months post-injury will be included in this study.

Participation will take approximately 2.25 hours over the course of 2 sessions. You will be asked to complete a 15 minute pre-screening telephone interview prior to the in-person interview. In person, you will be asked to complete a brief questionnaire and take part in a 2 hour one-on-one interview with a researcher in a private setting on campus or in the privacy of your own home. A summary of the interview will be sent to you two weeks later by email and you will have an opportunity to clarify any comments made. You may also be asked to take part in a follow-up interview which will be a maximum of 1 hour in length. We will offer \$20.00 to you for participating in the study to compensate you for your time and reimburse you for any travel expenses you may incur.

You may experience some discomfort due to the nature of the questions being asked; in this event, contact information for Dr. Gammage and student health services (905-688-5550 ext.3243, <http://www.brocku.ca/healthservices>), the Niagara Distress Center (905-688-3711, [www.distresscentreniagara.com/](http://www.distresscentreniagara.com/)), Spinal Cord Injury Ontario (1-877-422-1112, [www.sciontario.org](http://www.sciontario.org)) and [www.211Niagara.ca](http://www.211Niagara.ca) is provided. Information regarding body image concerns can be found at the following official website: [www.nedic.ca](http://www.nedic.ca). Please remember that there is normal variability in body sizes, shapes, functionality, and ability within the population and that diversity in all these aspects are normal.

Your participation will help describe body image experiences that are common for individuals who have a spinal cord injury. This information will aid in the development of interventions designed to help individuals with spinal cord injury to cope with body image experiences in their lives.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905-688-5550 ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca))

If you have any questions, please feel free to contact me.

Thank you

**Principal Investigator:**  
**Kimberley Gammage, Associate Professor**  
**Department of Kinesiology**  
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**905-688-5550 (x3772)**  
**[kgammage@brocku.ca](mailto:kgammage@brocku.ca)**

**Student-Investigator:**  
**Aly Bailey, Master's Student**  
**Faculty of Applied Health Sciences**  
**Brock University**  
**905-688-5550**  
**[ab12fa@brocku.ca](mailto:ab12fa@brocku.ca)**

**This study has been reviewed and received ethics clearance through Brock  
University Research Ethics Board (file #12-253)**

## Appendix C: Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (LTPA-SCI) Telephone Script

*INSTRUCTIONS: I am going to ask you about the time you spent engaging in mild, moderate, and heavy intensity LTPA in the last 7 days. Leisure Time Physical Activity (LTPA) is physical activity that you choose to do during your free time, such as exercising, playing sports, gardening, and taking the dog for a walk (necessary physical activities such as physiotherapy, grocery shopping, pushing/wheeling for transportation are not considered LTPA). Please refer to the intensity chart (next page) for descriptions of what mild, moderate and heavy intensity LTPA feel like.*

1. Mild intensity LTPA requires very light physical effort; mild intensity activities make you feel like you are working a little bit, but you can keep doing them for a long time without getting tired...

During the last 7 days, on how many days did you do mild intensity LTPA? \_\_\_\_\_  
On those days, how many minutes did you usually spend doing mild intensity LTPA?  
\_\_\_\_\_

2. Moderate intensity LTPA requires some physical effort; moderate intensity activities make you feel like you are working somewhat hard, but you can keep doing them for a while without getting tired...

During the last 7 days, on how many days did you do moderate intensity LTPA? \_\_\_\_\_  
On those days, how many minutes did you usually spend doing moderate intensity LTPA? \_\_\_\_\_

3. Heavy intensity LTPA requires a lot of physical effort. Heavy intensity activities make you feel like you are working really hard, almost at your maximum. You cannot do these activities for very long without getting tired. These activities may be exhausting.

During the last 7 days, on how many days did you do heavy intensity LTPA? \_\_\_\_\_  
On those days, how many minutes did you usually spend doing heavy intensity LTPA?  
\_\_\_\_\_

**How hard are you working?**

**NOTHING AT ALL**

Includes activities that even when you are doing them, you do not feel like you are working at all.

**MILD**

Includes physical activities that require you to do very light work. You should feel like you are working a little bit but overall you shouldn't find yourself working too hard.

**MODERATE**

Includes physical activities that require some physical effort. You should feel like you are working somewhat hard but you should feel like you can keep going for a long time.

**HEAVY**

Includes physical activities that require a lot of physical effort. You should feel like you are working really hard (almost at your maximum) and can only do the activity for a short time before getting tired. These activities can be exhausting.

**How does your body feel?**

Breathing &  
Heart rate

Everything is normal

Stays normal or is only a little bit harder and/or faster than normal.

Noticeably harder and faster than normal but NOT extremely hard or fast

Fairly hard and much faster than normal

Muscles

Feel loose, warmed-up and relaxed. Feel normal temperature or a little bit warmer and not tired at all

Feel pumped and worked. Feel warmer than normal and starting to get tired after awhile

Burn and feel tight and tense. Feel a lot warmer than normal and feel tired.

Skin

Normal temperature or is only a little bit warmer and not sweaty

A little bit warmer than normal and might be a little sweaty

Much warmer than normal and might be sweaty

Mind

You might feel very alert. Has no effect on concentration

Require some concentration to complete

Requires a lot of concentration (almost full) to complete

## **Appendix D: Interview Guide**

The purpose of this research project is to gain better insight on the topic of body image and what it represents for an individual with a spinal cord injury. This interview is designed to better understand body image in terms of the negative and positive experiences. As a new researcher in the field of body image, my passion is to better understand the experiences of having a physical disability. A lot of information is available on healthy able-bodied White women and men on their body image concerns. To date there is still very limited information available about body image in those who have a spinal cord injury. Body image research tends to focus largely on the negative components of embodiment, whereas I believe in the importance to better understand the positive experiences, especially for those who have a spinal cord injury. As a first year Master's student, my interest in research stems from the drive to expand knowledge on communities other than the healthy able-bodied population. As a new researcher, I have taken a particular interest in learning about the experience of having a spinal cord injury.

### **Part 1: Introduction**

- How did you hear about my research project and what made you want to participate?
- How do you like it here at the lab at Brock University?
  - How well do you know the trainers/ volunteers?
  - What are some of the best parts of being involved?
- Tell me about how physically active you were before your injury?
  - Any differences since your injury?
  - What are some of the benefits you have noticed with being active?
- Before your injury? After?

### **Can you tell me a bit about how you view your body?**

#### **Probing Questions:**

1. Now?
  - a. Before your injury?
  - b. Acutely after your injury?
2. Can you think of positive aspects of your body?
  - a. Negative?
3. What do you feel confident/ comfortable about in terms of your body now?
  - a. Less confident?
4. What areas of your body do *you* think are your best features?

### **Tell me about how you first adjusted to your body after your injury?**

#### **Probing Questions:**

1. What helped in your adjustment?
2. Who played a key role? How?
3. How might other people with a spinal cord injury adjust differently than you?

## **Part 2: Body Image**

**For the purpose of this study, body image is defined as a multidimensional concept which reflects how we see, think, feel, and act toward our bodies?**

2. Will you talk about how you **see** your body now?
  - a. How about before your injury?
  - b. How about acutely after your injury?
3. In what ways do you typically **think** about your body?
  - a. How about before your injury?
  - b. How about acutely after your injury?
4. Overall, how do you **feel** about your body now?
  - a. How about before injury?
  - b. How about acutely after your injury?
5. In what ways do you **act** towards your body?
  - a. E.g., some people engage in certain activities because of how they are feeling about their body.
  - b. E.g., Sometimes I spend more time at the gym if I'm feeling anxious about my body.

**What aspects do you think are important in regards to body image for someone who has a SCI?**

### **Probing Questions:**

- What are some typical daily thoughts about the body?
  - Functioning, health, appearance?
- How (if at all) has your injury directly affected your body image?

**What do you consider to be the ideal body?**

### **Probing Questions**

1. What did you consider to be the ideal body before your injury?
2. Has that changed since your injury?
3. Do you have a role model you look up to that you believe is the 'ideal'?

**How does the media impact how you feel about your body currently?**

### **Probing Questions:**

1. Tell me about a time the media may have influenced your thoughts/ideas about your body.
  - a. Does it influence how you feel about your appearance now? Why/why not?
2. How much did the media influence how you felt about your body before your injury?
3. Do you still feel pressured by western ideals of beauty since your injury?

**Tell me about how people in your life (partners, family, friends) affect your body image.**



**Probing Questions:**

1. How were people there for you when it came to adjusting to your injury in terms of your body image?
2. What are some examples of support that is needed after a spinal cord injury in terms of body image?
3. How have your relationships changed or stayed the same since your injury?
  - a. Has this affected your body image?

**Tell me about how engaging in physical activity made/makes you feel about your body.**

**Probing Questions:**

1. Why did/do you feel that way?
2. Why is it important/not important?
3. Why do you exercise/not exercise?

**Part 3: Positive Body Image**

**What do you think having a positive body image means?**

**What do you think having a negative body image means?**

**In what specific situations might someone with a SCI feel comfortable with their body?**

**Probing Questions:**

1. Are there specific places that are comforting? Where? Why?
2. Are there specific people someone may identify with being comfortable around? Who? Why?

**If Applicable:**

- Can you think of a time you felt comfortable with your body?
- What were you specifically thinking and feeling about your body in that situation?

**Tell me about something that may promote a positive experience with the body shortly or immediately after a SCI.**

**Probing Questions:**

1. Can you think of anything in the rehabilitation process that may promote a positive experience with the body?

**If Applicable:**

- Can you tell me about a time shortly after your injury that you felt good about your body and what caused that to happen?

**What are some ways someone with a SCI may see him or herself in a positive way?**

**Probing Questions:**

1. How might they see their appearance in a positive way?
2. How might they see the health of their body in a positive way?
3. How might they see the overall progression of their functionality of their body in a positive way?

If Applicable:

- Can you tell me about a time recently that you saw your body in a positive way?

**What are some examples of good thoughts a person with a SCI may have about their body?**

**Probing Questions:**

1. What are some examples of good thoughts about appearance (or other aspects)?

If Applicable:

- Can you tell me about some positive thoughts you have had about your body?

**How do you think people with a SCI in general go about feeling positive about their body?**

**Probing Questions:**

1. What are some typical emotions that may be associated with feeling positive about the body?
2. Tell me about some activities that might make someone feel good about their body.
3. How might someone with a SCI feel good in a different way than someone without a SCI?

If Applicable:

- Can you think of some things that make you feel good about your body?

**What are some ways a person with a SCI may act in a positive way towards their body?**

**Probing Questions:**

1. What types of behaviours may be more positive towards the body?

If Applicable:

- Can you tell me about ways that you act that are positive towards your body?

**How might someone with a SCI typically deal with negative information directed towards their body?**

**Probing Questions:**

1. What are some ways to deal *well/cope* with negative information?
2. How might people with a disability be appreciative of their body?

If Applicable:

- Can you tell me about a time you may have dealt well with negative information directed towards your body?

**How might someone with a SCI build a positive body image?**

**Probing Questions:**

1. What *factors* contribute to a positive body image for those with a SCI?
2. How might someone *learn* to feel good about their body with a SCI?

If Applicable:

- Can you tell me about how you learned to build a positive body image?

**Overall, what is your understanding of a positive view on the body and how might it be different for someone who has a spinal cord injury?**

**Is there anything else that you feel is important when it comes to feeling healthy and positive about the body, especially for someone with a spinal cord injury?**

**Great, thank you very much for your time and much needed information for this research project!**

## **Appendix E: Informed Consent**

**Date:** June 2013

**Project Title:** Exploring Body Image Experiences among Individuals who have a Spinal Cord Injury

**Principal Investigator:**

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### **INVITATION**

You are invited to participate in a research study that will explore body image in individuals who have a spinal cord injury. Only participants who indicate no previous history or diagnosis of a clinical eating disorder, who are 18 years of age or older and at least 12 months post-injury will be included in this study.

### **WHAT'S INVOLVED**

As a participant, you will be asked to complete a 15 minute pre-screening telephone interview, a brief questionnaire and take part in a one-on-one 2 hour interview with a researcher in a private setting on campus or in your own home. Participation will take approximately 2.25 hours of your time total over the course of both sessions. A summary of the interview will be sent to you two weeks later by email and you will have an opportunity to clarify any comments made. As well, you may be asked to take part in a follow-up interview which will be a maximum of one hour in length.

### **POTENTIAL BENEFITS AND RISKS**

We will offer \$20.00 to you for participating in the study to compensate you for your time and reimburse you for any travel expenses you may incur. Your participation will help describe body image experiences that are common for those who have a spinal cord injury. This information will aid in the development of interventions designed to help individuals with body image concerns to cope with body image experiences in their lives. There is a possibility you may experience some discomfort due to the nature of the questions being asked; in this event, contact information for Dr. Gammage and student health services (905-688-5550 ext.3243, <http://www.brocku.ca/healthservices>), Spinal Cord Injury Ontario (1-877-422-1112, [www.sciontario.org](http://www.sciontario.org)) or Distress Centre Niagara (905-688-3711, [www.distresscentreniagara.com](http://www.distresscentreniagara.com)) is provided. Information regarding body image concerns can be found at the following official website: [www.nedic.ca](http://www.nedic.ca). Please remember that there is normal variability in body sizes, shapes, functionality, and ability within the population and that diversity in all these aspects are normal.

### **CONFIDENTIALITY/ANONYMITY**

Anonymity cannot be offered in this study given the nature of the interview. Any information that arises from participants will be treated with confidentiality. Your name will not be included or, in any other way, associated with the data released from the study. Please do not place your name or any identifying information on the questionnaire. Data collected during this study will be stored in a locked filing cabinet of the research laboratory of Dr. Gammage at Brock University. They will be retained until five years past publication of the research. At this time, written documents will be shredded, and audiotapes and electronic files of the transcripts destroyed. Access to this data will be restricted to the research team.

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled (such as participation in the Neuromuscular Acquisition Lab at Brock University and being on the Brock Niagara Penguins Basketball Team). Your data will be withdrawn from the study and destroyed upon your request.

### **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available. At your request you may receive a summary of results by completing the request for summary of results form.

### **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the Research Team using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (file #12-253). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at 905-688-5550 ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca).

Thank you for your assistance in this project. Please keep a copy of this form for your records.

**CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: \_\_\_\_\_ (please print)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix F: Demographic Information**

Please complete the following information:

Age: \_\_\_\_\_

Ethnicity: \_\_\_\_\_

Height (if known): \_\_\_\_\_

Weight (if known): \_\_\_\_\_

Level of Injury: \_\_\_\_\_ Age at Injury: \_\_\_\_\_

Severity of Injury (circle one):

Complete/ Incomplete

Date of Injury: \_\_\_\_\_

Please indicate your AIS classification by circling one below:

A

B

C

D

E

Unknown